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ABSTRACT

This report examines policy-related trends and projections in the use of various Medicaid-funded care services for persons with mental retardation and related conditions, and identifies factors influencing these trends nationally and in the various states. The examination is based on three sets of research activities: analyses of databases on residential services for persons with mental retardation; a survey of all state mental retardation/developmental disabilities (MR/DD) agencies; and case studies of 10 states. Sections of the report examine: (1) the mission and commitments of state MR/DD agencies as they themselves identify them; (2) past, present, and projected patterns of residential services in the nation and in the various states, focusing on general trends and contributing factors in long-term care service provision, irrespective of the role of Medicaid; (3) past, present, and projected utilization of Intermediate Care Facilities for the Mentally Retarded, with states' considerations in weighing costs and benefits to themselves and service consumers of the various Medicaid options; (4) status of Medicaid Home and Community-Based Services programs within the different states and state perceptions of program strengths and limitations; (5) status of persons with mental retardation in nursing homes and the implications of Public Law 100-203 which requires states to review the appropriateness of those placements; and (6) state use of Medicaid options other than Intermediate Care and "Medicaid waiver" services. Appendixes contain literature-based behavioral outcomes associated with movement from state institutions to small community living arrangements and a copy of the interview form used in the case studies. (36 references) (JDD)

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Medicaid Services for Persons with Mental Retardation and Related Conditions

Project Report 27
May 1989

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Corrections

STATE OF FLORIDA
DEPARTMENT OF HEALTH AND REHABILITATIVE SERVICES

July 26, 1989

Mr. K. Charlie Lakin
Center for Residential and
Community Services
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University of Minnesota
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Minneapolis, MN 55455

Dear Mr. Lakin:

As you discussed with Susan Matus of my staff on July 19, 1989, we request that the following corrections be made to the Medicaid Services for Persons with Mental Retardation and Related Conditions publication.

Page 104: "The waiver's target population is clients with the highest level of need and those who are the costliest to serve."
Should read: "The waiver's target population is clients with the highest level of need who are often the costliest to serve."

Page 104: "All waiver service recipients are in supervised residential settings."
Should read: "Approximately 65% of waiver service recipients are in supervised residential settings."

Page 108: "... in contrast, the number of waiver recipients in Colorado is more than half the number of people in supervised residential placements, and more than 30% in Florida and Oregon."
Should read: "... in contrast, the number of waiver recipients in Colorado is more than half the number of people in supervised residential placements, more than 30% in Oregon and 28% in Florida.

We appreciate your willingness to include our comments as an attachment to the publication. My office has no record of receiving the draft materials your office sent out in March, 1989.

If you have any questions or comments, please contact Susan Matus at (904) 488-9545.

Sincerely,

Marcia Hall
for

Kingsley R. Ross
Assistant Secretary for
Developmental Services

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EXECUTIVE SUMMARY

Title XIX of the Social Security Act (Medicaid) is the primary program in the United States for funding residential and related services for persons with mental retardation and related conditions*. The largest of all Medicaid programs for persons with mental retardation and related conditions is the Intermediate Care Facilities for the Mentally Retarded (ICF-MR) program. It has been the focus of considerable attention by policymakers, program administrators and advocates in recent years. Interest in it has been stimulated by the size of ICF-MR expenditures ($5.6 billion in Fiscal Year 1987); the rate of growth in ICF-MR expenditures (from $1.1 billion in fiscal year 1977 to $5.6 in fiscal year 1987); the growth in the total number of ICF-MR beneficiaries (from 106,166 on June 30, 1977 to 144,350 on June 30, 1987); and the high average cost per beneficiary (about $37,600 per person in FY 1987). Attention to this program has been further heightened by considerable criticism of its perceived institutional orientation (in FY 1987, 86% of ICF-MR expenditures went to facilities of 16 or more residents which had an average population of 148 residents); this at a time when professional opinion and research findings consistently favor noninstitutional care. In sum there is concern that the ICF-MR program, enacted in 1971, is showing its age and has perhaps outlived its usefulness as the primary means of supporting residential and related services for persons with mental retardation and related conditions (MR/RC).

Recently there has been widespread interest in other Medicaid services for people with MR/RC. Of particular interest has been the Medicaid Home and Community-Based Services (HCBS) Waiver. It has responded to many of the specific criticisms of the ICF-MR program by supporting

---

*Mental retardation and related conditions (MR/RC) is used in Medicaid and in this report to refer to people who are determined to have *mental retardation* (MR) on the basis of an I.Q. below 70 and concurrent substantial limitation in "adaptive performance," including significant work-related limitation of function, restriction in activities of daily living, and/or difficulties in social functioning; or who are determined to have *related conditions* (RC) on the basis of severe, chronic disabilities, other than mental illness, which are evident prior to age 22 and result in substantial limitations in three or more of the following areas: self care, understanding and using language, learning, mobility, self-direction, or capacity for independent living. Related conditions are practically and statutorily equivalent to developmental disabilities (DD).

community-based alternatives to institutional care. To a lesser extent there has been interest in other Medicaid options for non-institutional services to persons with MR/RC, including case management and personal care. In addition, Title XIX as the primary source of funding for nursing homes has become a central focus of efforts to evaluate the appropriateness and possible need for changes in the living arrangements of an estimated 40,500 people with mental retardation in nursing and personal care homes nationwide. All of these programs and issues have to some extent been intermingled in significant proposals to substantially alter the ways that persons with mental retardation and related conditions are served through Medicaid programs.

The project described in this report was funded by the Health Care Financing Administration (HCFA) to examine policy related trends and projections in the use of various Medicaid-funded care services for persons with mental retardation and to identify factors influencing these trends nationally and in the various states. This examination was based on three sets of research activities: (1) analyses of several extant, longitudinal data bases on residential services for persons with mental retardation; (2) a survey of all state mental retardation/developmental disabilities (MR/DD) agencies regarding current and projected residential services policy and program utilization; and (3) in-depth case studies of ten individual states covering a broad range of issues related to residential and related services for their citizens with mental retardation and related conditions.

The Contemporary Context

The contemporary context dominating state policy on residential and related services includes a remarkably consistent set of philosophical and programmatic principles and an equally consistent set of problems and issues. The vast majority of states are moving steadily to increase community living opportunities and decrease institutional placements of their citizens with developmental disabilities. These efforts are guided by three recurring concepts or principles: normalization (affording the rights and benefits of culturally typical lifestyles), placement in the least restrictive environment, and community integration. These principles, coupled with a common theme that the most effective services are ones which can be individualized to respond to the specific characteristics and life circumstances

of each person, clearly guide the statements of mission and purpose of most state MR/DD agencies. From these statements, it is possible to identify recurring goals and objectives for residential and related services within a majority of states. These include:

- increasing use of community-based services and decreasing use of institutional care;
- increasing flexibility in responding to individual needs and developing a broader array of services and supports to respond to those needs;
- improving quality of services by better monitoring of individual settings and by increased access to the normalized life experiences, services and supports which are associated with increased independence, opportunities for self-determination, community integration, and/or productivity; and
- increasing supports to families with members with MR/RC at home and the involvement of families with members in out-of-home residential settings.

These increasingly proactive and value-driven goals of most state MR/DD agencies remain within the context of their traditional state responsibilities. Those responsibilities (or general missions) generally include: providing adequate and appropriate supplies of residential and related services; promoting optimal efficiency in the use of state resources; and assuring that minimum standards of quality are maintained by service providers.

In each of these areas of responsibility, most states note significant problems in carrying out their mission, including:

- difficulty in obtaining adequately increased funding to serve community-based populations which include greater numbers of people and more people with severe disabilities;
- difficulty in accessing federal program support for services responding to the guiding principles and service system objectives established by the states;
- difficulty in responding to a growing number of persons awaiting community-based services; and
- difficulty in adequately monitoring and assuring the quality of services in dispersed community settings.

Residential Services in General

The past decade has witnessed rather dramatic changes in the kinds of places in which housing is provided to persons with mental retardation and related conditions. Today, the service system for persons with mental retardation/developmental disabilities in most states serves more people

in community settings than in institutions. This trend has been supported by a substantial and growing body of research showing significant benefits of community versus institutional living in important areas, including development of basic skills and involvement in culturally typical activities. With only a few exceptions, states demonstrate commitment to continuing deinstitutionalization along with expansion of community living opportunities for their citizens with MR/RC.

Many findings of this study exemplify these general trends and commitments, including the following:

- *There has been continued institutional depopulation (deinstitutionalization)*: Deinstitutionalization became first evident in state institution population statistics 20 years ago. Since then there has been a continuing reduction in the use of large state institutions, from an average daily population of 194,650 in 1967 to 151,532 in 1977 to 94,696 in 1987.

- *There has been increased use of small facilities*: Over the past 10 years there has been a rapidly increasing number of people in facilities of 15 and fewer residents, from 40,433 in 1977 to 63,703 in 1982 to 118,570 in 1987. On June 30, 1987 the number of people with mental retardation in small residential facilities (118,570) was 86% of the number in large public and private facilities (137,133). In contrast on June 30, 1977 the 40,433 residents of small facilities were just 19% of the 207,363 residents in large facilities.

- *There has been a decreased rate of residential placement*: Between 1977 and 1982 the number of people with mental retardation in all public and private residential facilities for persons with mental retardation decreased from 120 per 100,000 of the general U.S. population to 106 per 100,000. However, since 1982 the rate has stabilized, remaining 106 per 100,000 in 1987.

- *There has been a rapidly decreasing average facility size*: The average number of residents per residential facility for persons with mental retardation decreased from 22 in 1977 to 7.5 in 1987. On June 30, 1987 the modal residential experience in terms of size (i.e., the size at which there were as many residents in smaller facilities as in larger facilities) was 17 residents; 10 years earlier it had been more than 300 residents.

- *There has been decreased placement of children and youth*: The number of children and youth (0-21 years) in public and private residential facilities for persons with mental retardation decreased from 91,000 in 1977 to 60,000 in 1982 to an estimated 48,500 in 1986. Children and youth in state institutions decreased from about 54,000 in 1977 to 12,024 in 1987.

- *There have been substantially reduced admissions to state institutions*: The 5,400 total admissions to state institutions in state fiscal year 1987 was approximately one-third the 14,900 total admissions in 1967, one-half the 11,500 total admissions in fiscal year 1977 and two-thirds the 7,850 total admissions in 1982. Reduced admissions to institutions has been the factor making the most significant contribution to the reduction of state institution populations (even more than discharges).

- *There have been restrictions placed on admissions to institutions*: Nationally 34 of 51 states have established specific restrictions on characteristics of and/or on the circumstances under which people can be admitted to state institutions.

- *There have been increased closures of state institutions*: Continued depopulation of state institutions and the high cost of spreading fixed costs over fewer residents is causing states to consider the necessity of closing whole institutions. A total of thirteen states reported/projected at least one institution closure between June 30, 1987 and June 30, 1990. States projected that by the end of this period at least 20 state institutions will have been closed.

- *Research has documented substantial benefits of community vs. institutional living*: Research over the past decade produced substantial support for the preferability of community living in areas related to life experiences and developmental outcomes. Between 1977 and 1988 a total of 17 studies assessed the developmental outcomes for over 1,300 persons discharged from large state institutions to community-based facilities for periods ranging from 6 months to 6 years. Thirteen of the 17 studies showed statistically significantly greater achievement in either overall adaptive behavior (if reported) or in the domains of basic self-care and domestic skills. The four remaining studies, while not obtaining a statistically significant association between deinstitutionalization and the development of adaptive behavior, all showed a tendency in this direction.

- *There has been continued rapid increase in state institution costs*: Since 1977 the annual cost of a year of state institution care increased from $16,144 to $54,516. In real dollars (controlled for inflation) this represented a nearly 80% increase.

- *There are continued differences in the characteristics of public institution residents and those of other types of facilities*: Nationwide, 60% of all residents of large public residential facilities (including about 4% county facility residents) were estimated to be profoundly retarded. This compares with 27% of large private institution residents, and 14% of small public and private residential facilities.

- *The trends described will continue through 1990*: States project that by June 30, 1990 their state institutions will house 83,334 residents, private institutions will house 40,984 residents, and community-based facilities of 15 or fewer residents will house 141,027 residents. Of the 265,350 persons expected to be in mental retardation facilities in 1990, states project that 53% will be in community-based facilities.

- *There has been a dramatic increase in recent years in the placement of people with the most severe of impairments in community-based settings*: The estimated 16,500 small, community facility residents with profound mental retardation represents an increase of more than 10,000 over the 6,200 small, community facility residents with profound mental retardation in 1982.

- *There remains huge variation among states in their reflection of the national trends noted above*: The extent of variability among states can be found in such statistics as percentage of total residents of mental retardation facilities in facilities of 15 or fewer residents (81% in 2 states to 13%), percentage of residents in nonstate facilities (83% to 22%), percentage of children and youth in residential care facilities for persons with mental retardation (35% in 2 states to 6%) and the percentage of children and youth in state institutions (48% to 1.5%). This variability relates to range of philosophical, historical, and policy differences among states, although the vast majority of states are moving in the general direction of the trends noted above.

- *States identify a wide range of factors influencing their residential services systems*: Factors external to state government noted to be major influences include court decisions and out-of-court settlements regarding institutional services; HCFA oversight of ICF-MR facilities, particularly the "look behind" activities; availability of the Medicaid Home and Community-Based Services waiver as a source of federal financing for noninstitutional services; and an increased and often unmet demand for residential and other services. Internal factors reported by states to be important in recent and

projected trends include policy decisions about agency goals; direct legislative or regulatory activity, such as limits on facility size or moratoria on ICF-MR development; policies affecting financing, including efforts to maximize federal financial participation (FFP), create incentives for community service development, and new reimbursement mechanisms/policies; and the development of related services with an impact on residential services, from special education to family supports.

- *States note two broad problem areas*: The two issues that states consistently describe as being most problematic in the area of residential services are 1) insufficient resources to fully meet goals for developing community services, as institutional expenditures continue to increase despite decreasing populations, and 2) extensive waiting lists for community residential care and other adult services, particularly for young adults exiting the special education system.

The ICF-MR Program

When Congress transferred the Intermediate Care Facility (ICF) program to Title XIX of the Social Security Act in 1971, it added the authorization for Medicaid funding for "care for the mentally retarded in public institutions which have the primary purpose of providing health or rehabilitation services and which are classified as intermediate care facilities" (House Report 12934-3). Prior to this legislation, federal participation in residential programs for persons with mental retardation was extremely limited. With enactment of this legislation, Congress sought to improve the quality of state institutional care. It also intended to tailor an institutional benefit specifically to the prevailing standards of appropriate care and treatment for persons with mental retardation. With passage of this legislation, the federal financial contribution to the cost of providing residential care to persons with mental retardation began to increase at a rapid rate; so too did the number of beneficiaries covered as more states entered the program and certified increasing numbers of residential facilities. While states continue to increase their expenditures under this program, they have stabilized their total beneficiaries. But like residential services in general the ICF-MR program is changing. Some of these changes and related findings from this study include the following:

- *After rapid growth following enactment, the ICF-MR program in recent years has achieved relative stability in the number of people served and this number is projected to decline by June 1990*: In the five-year period from June 30, 1977 to June 30, 1982, the number of ICF-MR facility residents grew from 106,166 to 140,684 (33%). In the subsequent 5 years, ICF-MR facility residents grew only another 3,666 persons (2.6%) to 144,350 on June 30, 1987. The number of ICF-MR residents actually decreased in a majority of states from 1982 to 1987 as states depopulated their state institutions, where most ICF-MR certified "beds" are located. States project that between June 30, 1987 and June 30, 1990 ICF-MR populations will decline by about 3,400 residents (2.3%).

- *ICF-MR expenditures have continued to increase*: Total ICF-MR expenditures for fiscal year 1987 were $5.6 billion, compared with $1.1 billion dollars in 1977. Total expenditures have moderated somewhat since 1982 ($3.6 billion) as the number of beneficiaries has stabilized.

- *There have been steadily increasing per beneficiary costs*: ICF-MR per beneficiary costs in fiscal year 1987 were about $37,600. This compares with $10,300 in 1977 and $25,600 in 1982.

- *In recent years there has been a decrease in the number of ICF-MR beneficiaries in institutions*: Between June 30, 1982 and June 30, 1987 the number of residents of ICF-MR certified units in state institutions decreased by 18,932 persons. The number of residents of large nonstate ICFs-MR increased by 8,786 producing a net decrease of just over 10,000 people in ICF-MR certified facilities of 16 or more residents. This compares with an increase of 25,400 between 1977 and 1982 when residents of ICF-MR units in state institutions increased from 93,249 to 107,358 and nonstate institution residents of ICF-MR units increased from 12,298 to 23,612. States project further decreases of almost another 10,000 (9,800) in large state and nonstate ICF-MR residents between 1987 and 1990.

- *States have continued to certify units of their state institutions*: On June 30, 1987, 93% of the 94,646 residents of large state institutions were residing in ICF-MR certified units. This compares with 62% on June 30, 1977 and 88% on June 30, 1982.

- *There has been continued growth of residents of small ICFs-MR*: On June 30, 1987 there were 23,528 persons in small ICFs-MR (2,874 in small state-operated facilities). This compares with 1,725 on June 30, 1977 and 9,714 on June 30, 1982. States project nearly 30,000 small ICF-MR residents by June 30, 1990.

- *ICF-MR resources remain concentrated in large institutions*: Despite growth in the number of small ICF-MR facilities; 84% of ICF-MR residents and 86% of federal ICF-MR expenditures were in large public and private facilities in 1987.

- *There has been a continued, although decreased, orientation to state institutions*: Despite increases in community-based ICF-MR facilities, program benefits continue to go primarily to state institutions, which had 63% of all ICF-MR residents and 72% of federal reimbursements in fiscal year 1987. In comparison 87.5% of residents and 93% of expenditures went to state institutions in 1977 and 76% of residents and 85% of expenditures were in state institutions in 1982.

- *There has been continued high variability among states in ICF-MR utilization*: Differences among the states in their use of the ICF-MR program as part of the state's overall MR/DD residential services system remained very large in 1987. Nine states had three-quarters or more of their residents in ICF-MR units; 4 states had less than 25%. In 1982 there were 10 states with 75% or more of their residents in ICF-MR units and 5 with less than 25%. Some of this variability is projected to decrease between 1987 and 1990. This projected change to greater uniformity will include the effects of Arizona and Wyoming entering the program for the first time, making ICF-MR a universally adopted state option under Medicaid.

- *There were substantial differences between ICF-MR and non-ICF-MR facility populations*: In 1987 about half (an estimated 49%) of ICF-MR residents were profoundly retarded. This compared with an estimated 14.5% of residents in noncertified facilities. Differences were most pronounced between certified and noncertified institutions of 16 and more residents, with 55% and 18% of their residents, respectively, being profoundly retarded and 12% and 34%, respectively, being "borderline" or mildly retarded. Differences in the populations of community-based ICFs-MR and noncertified community-based facilities were much less pronounced, with an estimated 17% of the ICF-MR

population and 12% of the non-ICF-MR population being profoundly retarded. Residents with borderline or mild mental retardation made up 30% of the population of both ICF-MR certified and noncertified facilities.

- *The distribution of ICF-MR residents by level of retardation changed little between 1982 and 1987*: In 1982, 50.0% of ICF-MR residents were profoundly retarded and 25% were severely retarded. In 1987 comparable estimates were 49% and 21% respectively. Among small ICF-MR residents in 1982, 16% were profoundly retarded and 27% were severely retarded. In 1987 comparable estimates were 17% and 25%. However, the total number of persons with profound and severe mental retardation living in community ICF-MR facilities increased over the 5 years from about 4,200 to 9,900.

- *Economic considerations remain primary in decisions regarding ICF-MR option use*: States report a range of economic considerations affecting their policy decisions regarding utilization of the ICF-MR option. These range from efforts to maximize participation by targeting deinstitutionalization first to noncertified units of state institutions or by certifying existing private institutions, to efforts to reduce total ICF-MR capacity or at least the rate of ICF-MR facility growth, especially for individuals considered able to be served in less costly noncertified alternatives. States generally observe that unless the ICF-MR option is used judiciously it can add significantly to the overall cost of providing appropriate residential services.

- *Access to Home and Community-based Services has substantially affected use of the ICF-MR option*: States consider the HCBS waiver, which permits Medicaid funding of non-ICF-MR alternatives for persons needing long-term care, to be a major influence on decisions regarding ICF-MR development. In general they consider it to have permitted much less development of small ICFs-MR than otherwise would have occurred.

- *Anticipation of significant federal Medicaid reform has affected some decisions about state ICF-MR programs*: A minority of states cite Medicaid reform proposals, and most notably the Medicaid Home and Community Quality Services Act of 1989 (S. 384), and its earlier versions, as playing an important role in decisions regarding long-term development of ICF-MR facilities. However, many states note that while they don't make decisions based on anticipation of federal Medicaid reform, they have made policy decisions that are congruent with major provisions with the reform proposals, notably in limits on the size of new community-based facilities.

- *States report numerous internal policies of importance to the development of ICF-MR services*: Internal policy actions related to ICF-MR use are common and ranged in 1988 from rules limiting new ICF-MR development to small facilities (typically five or six beds) to reimbursement reform (both cost-cutting measures and efforts to improve rate equity), to moratoria on new ICF-MR development. Growing ICF-MR costs are noted as the most common impetus for internal state policy activities.

- *Quality assurance and appropriateness of care within the ICF-MR program are issues of importance in many states*: In many states considerable tension is noted between cost containment initiatives and concerns and the need for basic expenditures to improve or maintain the present quality of care. In most states pressures for improving the quality and monitoring of existing programs is competing financially with the need to serve people on the waiting lists that are substantial and growing in most states.

- *States report ambivalent reactions to HCFA "Look Behind" reviews*: States generally consider "Look Behinds" as necessary but difficult experiences. A lasting effect in many states was said to be costs of meeting standards in state institutions that leave insufficient resources for community-based residential services. Some states note the reviews have improved institutional conditions, but with

more time and/or resources they would have preferred to have met requirements through deinstitutionalization.

- *Many states express concern about interpretation of the new (June 1988) ICF-MR regulations*. States are especially concerned about how HCFA will interpret and monitor the standards for the provision of active treatment. These concerns were expressed not only for the ICF-MR program, but also for the active treatment required to be provided to persons with mental retardation remaining in nursing facilities.

The Home and Community-Based Services (HCBS) Waiver

The Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35) contained provisions granting the Secretary of Health and Human Services the authority to waive certain statutory requirements to permit states to finance a number of noninstitutional services through the Medicaid Program. To receive such services beneficiaries must be Medicaid-eligible and likely to need institutional services (i.e., nursing home or ICF-MR) in the absence of the Home and Community-Based Services. States are permitted to exercise considerable flexibility in the services they provide under an approved plan, but total federal funds are restricted to the savings in institutional expenditures made possible by the alternative services (i.e., "cost neutrality" must be demonstrated). The Medicaid Home and Community-Based Services (HCBS) waiver is of significant and growing importance to state MR/DD service systems. States with HCBS authority and those in the process of applying for it cite its flexibility, its support of community-based residential options, and its availability for services that may obviate or delay institutionalization as keys to its attractiveness. Recent national trends in state utilization and observations by states regarding Medicaid Home and Community-Based Services include the following:

- *The number of states participating in the program is increasing*: On June 30, 1987 a total of 35 states were providing Home and Community-Based Services to persons with mental retardation/developmental disabilities. Five additional states have since obtained approval to provide Home and Community-Based Services.

- *The program has experienced steady growth in beneficiaries*: The Medicaid HCBS waiver option was enacted in 1981 and, therefore, steady growth in beneficiaries in its early years was expected in the first half of the decade. Between June 30, 1985 and June 30, 1987 the total number of waiver service recipients grew only 8% (or 2,438 individuals to a total of 22,700), but the relatively low rate of growth was due primarily to a huge reduction of about 4,350 beneficiaries in Florida. Excluding Florida, total waiver recipients grew by 26% between June 30, 1985 and 1987.

- *Statistics for FY 1988 show a particularly large one year increase in waiver beneficiaries and expenditures*: Reported waiver recipients for FY 1988 increased to 29,450 from 22,700 in FY 1987 (29.7%). Expenditures increased to about $450 million (from $294 million) during the year. Six

states accounted for 63% of the increase in beneficiaries and 61% of the increase in costs (NASMRPD, 1989).

- *The HCBS shows very favorable cost comparison with ICF-MR services*: Annual HCBS costs in 1987 were $294 million or about $13,200 for each recipient as of June 30, 1987. Comparable costs for ICF-MR services in 1987 were $37,600 per recipient.

- *The HCBS program is substantially coinvolved in deinstitutionalization efforts in most states*: Most states utilize reductions in state institution populations to demonstrate "cost-neutrality" of Home and Community-Based Services. A number of states have also shown reductions in large private ICF-MR populations to obtain authorization to serve individuals under the HCBS waiver. A majority of all states, and a vast majority of states with approved waivers, consider the HCBS program to play an important role in developing smaller community-based alternatives to institutional living.

- *There is considerable consistency in service use among states*: States universally offered some form of habilitation services as part of their waiver programs, including day habilitation programs, residential facility-based training, behavioral intervention services, and early intervention services. Case management, respite care, and personal and/or supervisory care (notably direct care in residential settings) were authorized for 80% of states requesting waivers.

- *States use HCBS primarily for residential and related services to persons with relatively severe disabilities*: Case study states report relatively few differences between waiver recipients and residents of ICF-MR facilities. Both groups tend to be made up primarily of persons with severe and profound mental retardation and who are receiving long-term care and habilitation. Among 10 case study states, which had approximately 45% of waiver recipients nationwide, an estimated 84% of waiver beneficiaries were in non-family, supervised residential settings.

- *There has been stabilization in total ICF-MR and HCBS recipients*: Total ICF-MR and waiver recipients increased only from 164,955 on June 30, 1985 to 166,868 on June 30, 1986 to 167,039 on June 30, 1987 (1.25% over the two years). In comparison combined expenditures grew from $4.93 billion to 5.90 billion (16.4%) over the same two year period.

- *The strength of the HCBS waiver to states is its consonance with their policy objectives*: In recent years states have focused the policy objectives primarily on areas of community and family living and on developing arrays of services that respond to individual characteristics and life circumstances. The flexibility of HCBS is virtually universally acknowledged by states as permitting them to pursue these goals with much needed federal financial participation in ways not possible under other Medicaid programs.

- *The waiver has helped states to demonstrate the potential of small, non-institutional residential options*: A number of states noted that HCBS have been a primary vehicle to demonstrate the feasibility of noninstitutional service approaches for people with severe disabilities, including challenging physical, health, and behavioral conditions.

- *The primary limitation cited by states is the cost-neutrality requirement*: States participating in the HCBS program, as well as those who do not, cite restrictions in waiver expenditures to savings in institutional expenditures as the program's major limitations. This limitation has resulted in the restriction of available funding, in the number of persons allowed to benefit, and in many states in the kinds of persons allowed to benefit. In a few states people with severe cognitive, physical and/or behavioral impairments were reported to have very limited access to community services because of the cost limits on Medicaid waiver services.

Persons with Mental Retardation in Nursing Homes

Growing concerns about the inappropriate placement of people with mental retardation in nursing homes, especially those who are nonelderly or who do not have significant medical or nursing needs, led to enactment of nursing home reforms in the Omnibus Reconciliation Act of 1987 (P.L. 100-203). The act requires transfers to more appropriate settings for many current nursing home residents with mental retardation and other developmental disabilities found not to require nursing services. Exceptions can be made for individuals who have resided in a facility 30 or more months, provided the individual chooses to stay and his/her "active treatment" needs are met. The Act also calls for pre-admission screening measures to prevent future inappropriate admissions. Data summarized in this report support the basic premises underlying the requirements of P.L. 100-203. Among these findings are the following:

- *There is continued substantial use of nursing homes as residential settings*: There are approximately 26,000 nursing and personal care homes nationwide, according to the Inventory of Long-Term Care Places. Of these there were 8,300 homes indicating one or more residents with mental retardation, and a total of 39,527 residents. This estimate is very close to the estimate of 40,539 persons with a primary diagnosis of mental retardation in nursing home facilities, reported in the National Nursing Home Survey of 1985.

- *There is widely varied use of nursing homes from state-to-state*: The 1986 Inventory of Long-Term Care Places, which surveyed all known nursing and related care facilities in the U.S. indicated that a total of 18 states had 1,000 or more residents with mental retardation in nursing and related care homes in 1986; nine states had more than 1,500. In contrast 15 states had fewer than 200 persons with mental retardation in nursing and other care homes.

- *Persons with mental retardation represent a decreasing proportion of total nursing homes residents*: In 1977 persons with a primary diagnosis of mental retardation made up an estimated 3.4% of the total population of an estimated 1,303,100 nursing home residents. In 1985 they made up an estimated 2.7% of an estimated 1,491,400 nursing home residents.

- *Nursing facilities house a relatively older population of persons with mental retardation*: An estimated 56% of nursing home residents with a primary diagnosis of mental retardation in 1985 were 55 years and older. Thirty-two percent were 65 years or older. These are virtually identical to the 55% and 32% estimates obtained in 1977. They present a substantial contrast with the June 30, 1987 findings of 12.1% of state institution residents being 55 years or older and 5.8% being 63 years or older.

- *Other than age there is general similarity between nursing home residents and residents of facilities for persons with mental retardation*: About 20% of the nursing home residents with mental retardation were reported to need assistance or special equipment for mobility; 80% were reported to need some assistance in bathing; about 60% to require some assistance in dressing; and 25% of the residents with mental retardation reported to have a bladder control problem or had an

ostomy, catheter or other device. This compares with an estimated 23% needing assistance or equipment for walking, 60% said to need help bathing, 53% to need help dressing, and 32% reported to have bladder control difficulty in a national sample of residents of public and private residential facilities for persons with mental retardation in 1987.

- *The projected impact of P.L. 100-203 varies among the states*: Just as they vary substantially in their historical use of nursing homes as a residential care option for people with mental retardation and related conditions, states vary substantially in the expected consequences of P.L. 100-203. Many states have reduced use of nursing homes for this population over the past few years and have initiated pre-screening activities. Since the enactment of P.L. 100-203, most states have conducted at least a preliminary review of the nursing home population to begin planning their implementation strategy. In the ten case study states, from 30-40% of the nursing home residents with mental retardation might be expected to require transfer to a more appropriate placement. States which have used nursing homes tend to expect this proportion to be greater than 40%.

- *States are concerned about the potential impact of P.L. 100-203 on community services*: Many states assume that implementation of P.L. 100-203 will place significant pressures on their community services systems. Some states indicate that it may slow states' ability to respond to persons awaiting any form of long-term care services. Several states indicate the provisions of P.L. 100-203 will slow deinstitutionalization by utilizing placements that would have gone to state institution residents. A few states indicate that some nursing home residents will probably be placed in state institutions. Most states plan to use the special Home and Community-Based Services waiver option directly linked to nursing home population reductions as the means of financing alternative community placements. Clarification of specific provisions in relation to active treatment requirements for individuals with mental retardation and related conditions who remain in nursing homes, as defined in standards for ICF-MR care, also is being awaited with much state interest.

Other Medicaid Options

According to Social Security Administration beneficiary samples an estimated 750,000 persons with mental retardation and related conditions are recipients of Supplemental Security Income (SSI). These persons generally qualify for Medicaid services offered in the various states on the basis of their being SSI recipients, although a few states have set Medicaid eligibility standards that are somewhat more restrictive. States participating in Medicaid are required to offer several specific medical services to categorically Medicaid-eligible people. In addition, states may choose to provide any one of 32 optional services in the state Medicaid program (one of which is ICFs-MR). Medicaid-eligible persons with mental retardation and related conditions, therefore are eligible for a wide range of services including physician services, inpatient and outpatient hospital services, laboratory and X-ray services, and dental services. In addition to services which respond to the general medical needs that persons with mental retardation share with the general population of Medicaid recipients, there are some

Medicaid options which may be of more specific relevance to the needs of persons with mental retardation. These include three options, which are widely included in HCBS waiver programs: case management, personal care, and clinic or rehabilitation services. A fourth "option" of growing interest to states is the authorized extension of categorical eligibility for Medicaid to children whose illnesses or disabilities might necessitate institutionalization if they did not live at home and who would be Medicaid eligible if institutionalized ("TEFRA-134" coverage). Findings from this study regarding these options include the following.

- *A majority of all states offer case management, personal care, or rehabilitative services in their HCBS waiver, but a minority tailor them as state option services to serve persons with mental retardation*: The most popular of the optional services was targeted case management. Twenty states reported utilizing or presently considering utilization of the service. Personal care, which is in the Medicaid state plan of half the states, is used specifically for persons with mental retardation and related conditions in only 9.

- *Only 3 states report exercising the option providing Medicaid eligibility for children and youth with mental retardation at home*: A total of 22 states are reported by HCFA to elect to provide Medicaid coverage to certain specific subpopulations of children who without medical assistance would be at risk of institutionalization. However, only three states report children and youth with mental retardation to be specifically targeted. Because this is a new Medicaid option, it is hard to judge the eventual level of participation. A number of states noted they wish to see the experience of other states before modifying their Medicaid eligibility criteria.

- *States note substantial potential in a number of optional services*: States would very much like the option of being able to use the case management, personal care, and clinic/rehabilitative services options to support services for persons with mental retardation. They view them as potentially able to contribute in important specific ways to existing needs among states for increased case management and monitoring, community living opportunities, and program of habilitation and training.

- *States consider the options as potentially reducing or delaying the need for institutional Medicaid services*: States note that the ability to provide day habilitation services under Medicaid's clinic or rehabilitative services options would reduce incentives to place persons in ICFs-MR. In the latter Medicaid pays not only for the day program as facility-based or contracted "active treatment," but also for the generally much more costly residential component. Similarly states which have placed persons in Medicaid funded personal care settings have found them considerably less costly than ICFs-MR.

- *States are concerned about the appropriateness/acceptability of using state options*: Despite the perceived desirability, states noted considerable lack of confidence about initial and continuing federal acceptance of efforts to develop and tailor such services to the needs of persons with mental retardation. States cite negative experiences of other states and perceived inconsistencies in federal interpretation of appropriate/inappropriate use of options as diminishing the likelihood of using state options for persons with mental retardation.

- *Some states express concerns about the restrictiveness or overly medical nature of some options*: While most states would like access to funding for habilitation services or non-institutional personal care through Medicaid for persons with mental retardation some states viewed their current conditions as being too restrictive, overly medical, and/or not cost-effective for wide-spread use with persons with mental retardation and related conditions.

Summary and Conclusions

Recent statistics on services for persons with mental retardation and related conditions indicate continued evolution of long-term care systems toward a predominantly community orientation. By Fiscal Year 1987 the average daily population of state institutions had decreased to less than half the population of 20 years earlier, with only 37% of the June 30, 1987 residential populations housed in state institutions. On June 30, 1987, 46.5% of all persons in residential settings for persons with mental retardation were living in community settings, and states project that by June 30, 1990, 53% will be in community facilities. Even nursing homes, which have had relatively stable populations of about 40,000 residents with mental retardation since 1977, will be compelled under P.L. 100-203 to move thousands of these individuals into mental retardation facilities. Most will enter community settings. Today, community services can no longer be viewed as merely an alternative to institutional care. In most states they are currently or will be shortly the primary model of care. Findings of this study suggest urgency in the federal government's recognizing a future in which community care will be predominant by reforming Medicaid in ways that assist in responding to a range of critical problems facing state community services systems:

- *States need a form of financial participation from the federal government that is not determined by where one is placed*: The level of participation of the federal government in institutional programs through Medicaid is much greater in total funds and proportion of beneficiaries than community-based programs. While 88% of all residents of large institutions are in Medicaid-funded ICFs-MR, only about a quarter of community facility residents had Medicaid participation in their care from either the ICF-MR or Medicaid waiver program. The primary source of federal contribution to community living for persons with mental retardation remains SSI. But its federal contribution to community living for persons with mental retardation was about one-fifth the average daily ICF-MR federal contribution in fiscal year 1987. States are reluctant to develop small facilities meeting the institutional ICF-MR standards simply to meet ICF-MR standards. They note preference for service decisions based on the principles of individualization, purchasing services rather than facilities, and maintaining flexibility in program options, but observe that it is not fiscally possible to base policy on such factors when large amounts of federal financial support lie in the balance.

- *States need flexibility in the services they may provide under Medicaid*: States nearly universally viewed their experience with Medicaid Home and Community-Based Services as positive. Criticism

of the program is largely limited to administrative issues related to its limitations on expenditures and its temporary approval provisions (3 years for new applications, 5 years for renewals). States are generally philosophically committed to providing services and supports based on individual needs. When presented with a specific legislative proposal providing broad flexibility in the range of services that could be offered under Medicaid (S. 384, the Medicaid Home and Community Quality Services Act of 1989), 38 of 51 state respondents in 1988 indicated agency support of the legislation, despite conditions which might reduce some federal contributions to their large institutions. A few states noted specifically that their support indicated only a preference of S. 384 to current Medicaid programs. Although it was introduced after the state survey was mailed, it seems highly predictable that state response to the Medicaid Community and Facility Habilitation Amendments (H.R. 854) would also reflect strong preference over current Medicaid programs, but with many reservations about "federalization" of quality assurance for community services.

- *The rates at which states are creating community living opportunities for their citizens suggests a possible desirability of proactive federal involvement*: A substantial body of research shows substantial and consistent benefits accrue to people with mental retardation when they move from large institutions to community facilities. In the 1987 Developmental Disabilities Act Congress noted that "it is in the national interest to offer persons with developmental disabilities the opportunity, to the maximum extent feasible, to make decisions for themselves and to live in typical homes and communities where they can exercise their full rights as citizens." Very impressive progress is generally being made in this direction nationally and in most states. But in a number of states, this "national interest" is being poorly attended to. It may be that simply "leveling the field" between Medicaid support of institutional and community services as proposed in H.R. 854 may be sufficient to encourage all states to move in the direction ostensibly supported by Congress and clearly supported by prevailing professional standards. But in a few states incentives to reduce institutional populations by reducing real dollar federal contributions for such care as proposed in S. 354 may well serve the national interest as defined by Congress.

- *States need substantially increased sources of funding for community services to meet current and projected needs*: Most states are currently reporting substantial numbers of persons awaiting entry into their services system. They also note substantial difficulties in obtaining funding to cover the costs of persons leaving state institutions, because most states have not been able to reduce institution costs as populations have decreased. Between 1982 and 1987 state institution populations decreased by 19% while total expenditures increased by 12%. Because of a shortage of funding states observe a wide range of problems including: insufficient number of programs are being developed, community facilities are inadequately compensated, community staff are considered underpaid with related problems of staff turnover, inadequately qualified staff, and insufficient funding for staff training all being evident within current community-based program.

- *States need to respond to large numbers of persons awaiting community services*: States report large and growing numbers of persons awaiting services. A number of factors are identified as contributing to this problem. These include limited growth in total residential capacity in the past 10 years, an unprecedented proportion of the population in the young adult years (18-39) in which most persons enter residential care, increasing longevity of persons with mental retardation, parental refusal of the unused capacity in institutions. Most states are not optimistic about improvements in this situation in the near future as a range of factors including limited funding for new facilities, inadequate funding to stimulate a provider market, and demands of court orders, laws and state policy focused primarily on bringing residents of mental retardation institutions and nursing homes to community settings. Despite the growing need, the only legislative proposal to date that would explicitly prohibit indefinite denial of services to certain individuals (persons defined as severely handicapped) was a 1988 proposal by a working group on federal programs for persons with MR/RC within the U.S. Department of Health and Human Services.

- *States acknowledge significant limitations in monitoring and directly contributing to quality of life in community facilities*: Minimal quality assurance and efforts to improve the quality of life of persons living in community settings is increasingly noted as a problem for states. Case management resources are frequently seen as too limited to establish caseloads permitting adequate involvement with "clients" to insure quality. Procedural monitoring activities are impaired by limited resources in an era of increasingly dispersed sites. Increasing efforts to establish citizen monitoring by advocacy groups and a few state agencies remains in relatively early states of development. After years of extremely limited federal oversight of community programs, relatively little among community ICFs-MR and none for waiver services and state-funded programs, there is substantial variation within and across states in the nature, amount, and perceived effectiveness of quality assurance. One important factor in these differences is the special Medicaid matching rates for quality assurance as part of states' ICF-MR survey and certification and inspection of care activities, while quality assurance for Medicaid waiver services and state funded programs must be nearly entirely supported with state funds. States also vary in their promotion of higher quality through training and technical assistance supports. A number of states consider the limited qualifications of staff recruited and the inability to retain experienced staff as a major issue in providing quality services. Differentiating the relative need for more extensive resources for state monitoring and technical support of service providers as opposed to more stringent or detailed federal standards for community services could not be determined from this study, though states strongly prefer the former.

INTRODUCTION AND METHODOLOGY

Background

In 1971 Congress added authorization within Title XIX of the Social Security Act for Medicaid funding of "care for the mentally retarded in public institutions which have the primary purpose of providing health rehabilitation services" (House Report 12934-3). Prior to enactment of the new Medicaid benefit for persons with mental retardation and related conditions (MR/RC)* in Intermediate Care Facilities for the Mentally Retarded (ICFs-MR) federal participation in services for such persons was extremely limited. Since 1971, federal programs and funding for persons with mental retardation has been expanded tremendously. Still no single program funding services for persons with mental retardation and related conditions has received more direct attention in recent years than Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF-MR) program. The ICF-MR program offers federal financial participation (FFP) for services provided to Medicaid eligible individuals in residential settings meeting comprehensive standards in areas such as supervision, habilitation services and health care. Eligibility for ICF-MR services is limited to individuals with a diagnosis of mental retardation or a related condition, such as cerebral palsy, who have been determined to be in need of "active treatment" and the ICF-MR level of care, in addition to any state imposed income and resource criteria.

A primary reason for attention to the ICF-MR program is its sheer size. Federal and state ICF-MR expenditures in Fiscal Year (FY) 1987 totalled 5.6 billion dollars, which was 54% of the estimated total of all non-educational noncash assistance expenditures (10.3 billion dollars) for persons with mental retardation and related conditions in the United States. Over the course of FY 1987, claims for reimbursement of ICF-MR services were made by states on behalf of a total of 148,960 individuals (with

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*Mental retardation and related conditions (MR/RC) is used in Medicaid and in this report to refer to people who are determined to have *mental retardation* (MR) on the basis of an I.Q. below 70 and concurrent substantial limitation in "adaptive performance," including significant work-related limitation of function, restriction in activities of daily living, and/or difficulties in social functioning; or who are determined to have *related conditions* (RC) on the basis of severe, chronic disabilities, other than mental illness, which are evident prior to age 22 and result in substantial limitations in three or more of the following areas: self care, understanding and using language, learning, mobility, self-direction, or capacity for independent living. Related conditions are practically and statutorily equivalent to developmental disabilities (DD).

a total of 144,350 persons residing in ICF-MR certified facilities on June 30, 1987). The average per beneficiary expenditure for ICF-MR care in Fiscal Year 1987 was $37,600.

A second reason for attention to the ICF-MR program is the perception that, because of its original focus on improving conditions in state institutions, it is overly oriented toward the typical service provision practices, organization, and environmental conditions of large institutions, with relatively little attention to the quality of life or personal development of their residents. Recent revisions of the ICF-MR regulations (June, 1988) have attempted to respond to this general criticism in significant ways. A third reason for attention to the ICF-MR program has been that access to the FFP it provides is limited to people residing in relatively restrictive ICF-MR certified facilities. A significant response to this criticism is the Medicaid Home and Community-Based Services waiver ("Medicaid waiver") program. This program was enacted in 1981 to provide Medicaid funding for alternative home-based and community-based services, such as case management, habilitation services, homemaker services, respite care, and other non-medical services, which may have the effect of preventing or delaying entry into Medicaid certified long-term care settings. For persons with mental retardation and related conditions, the "waiver" program is focused primarily on providing an alternative to ICF-MR placements. In FY 1988 a total of 29,446 persons received home and community-based services through "the waiver," which during the fiscal year cost about 450 million dollars. The average per beneficiary cost to Medicaid of this program in 1987 was about $15,300.

In addition to the ICF-MR and Medicaid waiver services programs, there is a range of other services under Medicaid which states can choose to provide to their citizens who qualify for Medicaid. Some of these options can be used to provide needed services to a significant number of persons with mental retardation and other developmental disabilities. These optional services include case management, personal care and habilitation services, and extension of categorical eligibility for Medicaid to children with disabilities living at home who require a level of care provided by Medicaid institutions and who would be Medicaid eligible if institutionalized.

Because Medicaid is an open-ended entitlement program with the federal government reimbursing a minimum of 50% of Medicaid costs (in 12 states) to 80% (Mississippi), based on state per capita income, many states are strongly attracted to participation in the various Medicaid options by expanding the range of covered services or the eligible population or both. More recently, however, a growing number of states are articulating the view that a significant number of people needing long-term care services cannot be well served or cost-beneficially served under current ICF-MR program options. These perceptions are reflected in a stabilization of the total number of ICF-MR residents since 1985, and states' projections that nationally the number of ICF-MR residents will decrease over the next few years. Concerns about the ability of the ICF-MR program to serve people appropriately and cost-effectively have prompted most of the states to seek new and expanded opportunities to apply the favorable Medicaid federal financial participation to a broader range of services for persons with MR/RC. The most important of these options, the Medicaid home and community-based services waiver ("Medicaid waiver") program, has provided a highly attractive and rapidly growing alternative to ICF-MR services for states. However, this option has significant structural limitations on the extent to which it can be used by states. But increasingly states are seeking individually and collectively to effect major reform in services available to people with MR/RC under Medicaid. Two major proposals that would do this are presently before Congress.

Purpose and Methodology

This examination of Medicaid services for persons with mental retardation and related conditions was based on a set of interrelated activities that were supported fully or in part by the Health Care Financing Administration. The primary purpose of the project was to examine trends and projections in Medicaid-funded and other long-term care services for persons with mental retardation and related conditions and the factors which influence utilization of these services in the individual states. Areas of focus included overall state utilization; characteristics of beneficiaries; state considerations and motivations in utilizing ICF-MR, Medicaid Home and Community-based Services (HCBS), and Medicaid options; and contemporary considerations and problems facing states in funding long-term care through

Medicaid or by other means. The three basic sets of research activities underlying this report were a longitudinal analysis of extant data bases, a national survey of state MR/DD agencies, and case studies of ten individual states. The report draws on information obtained through all three of these activities to respond to basic themes in past and present decisions of states with respect to the use of the various Medicaid options for persons with mental retardation and related conditions.

Longitudinal Analysis of Extant Data Bases

The purpose of the longitudinal analyses of existing data bases was to obtain descriptive information on the trends and current status of residential services for persons with mental retardation and related conditions, including ICF-MR services. The most comprehensive longitudinal data bases on state-licensed or state-operated residential services were identified for this purpose. These included:

- the 1977 census survey of 11,025 residential facilities in operation on June 30, 1977 by the Center for Residential and Community Services (CRCS), University of Minnesota;
- the 1982 census survey of 15,633 residential facilities in operation on June 30, 1982 by CRCS;
- the 1986 census survey of 14,639 residential facilities for persons with mental retardation in operation in and around April 1986 by the Center for Health Statistics, Department of Health and Human Services;
- the 1987 National Medical Expenditure Survey, Institutional Population Component-Mental Retardation Facilities (a national sample survey of 691 facilities and 3,618 of their residents);
- the 1977 National Nursing Home Survey (a national sample survey of 1,451 facilities and 181 of their residents with mental retardation); and
- the 1985 National Nursing Home Survey (a national sample survey of 1,079 facilities and 144 of their residents with mental retardation).

Surveys of All State MR/DD Agencies

Two separate surveys were conducted of state mental retardation/developmental disabilities (MR/DD)* agencies in each of the states. These included:

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*By state mental retardation/developmental disabilities (MR/DD) agencies, this report includes the agencies in each state designated as state "mental retardation" agencies, (21 states), "mental retardation/developmental disabilities" agencies (8), "developmental disabilities" agencies (20), or agencies designated in other ways but having primary responsibility for persons with mental retardation and related conditions (2).

- a survey of all states to gather statistics on state beneficiaries of ICF-MR and Medicaid HCBS services by size and operation of facilities and services provided; and
- a survey of all states to gather information on projected use of Medicaid options for persons with mental retardation, factors influencing utilization of those services and other general policy topics related to residential and related services, and to obtain relevant state plans and state-sponsored research and other reports.

Case Studies of 10 States

Ten states were selected in consultation with HCFA staff for detailed case study interviews regarding their residential and related services for persons with mental retardation and related conditions. The states selected included California, Colorado, Connecticut, Florida, Indiana, Minnesota, Mississippi, New York, Oregon, and Texas. States were chosen to insure geographical distribution as well as a number of other factors, including preference for large states with the greatest potential/actual impact on Medicaid expenditures (California, New York, Texas). In addition states were ranked and selected on the basis of intensity of use of the ICF-MR option (Minnesota, New York, Texas); intensity of use of Medicaid waiver option (California, Colorado, Florida, Minnesota, Oregon); and projections of major increases (50+%) in community facility residents from June 30, 1987 to June 30, 1990 (Connecticut, Indiana). Mississippi was included primarily as a relatively low user of Medicaid, despite its 79.65% federal matching rate for medical assistance (i.e., for every 5 dollars spent on Medicaid approved services in Mississippi the federal government reimburses 4 dollars). Interviews were conducted with directors of state MR/DD agencies or their designates for the selected states and current policy and planning documents were reviewed. The discussion guide for these case studies is included in the Appendix of the report.

Overview of the Paper

This report is organized with the intent that each part will provide context for each successive Part. Part I examines the contemporary mission and commitments of state mental retardation/ developmental disabilities (MR/DD) agencies as they themselves identify them. This discussion will examine what states are attempting to accomplish for their citizens with mental retardation and related conditions. Part II of the report examines past, present, and projected patterns of residential services

in general in the nation and in the various states. It examines general trends and contributing factors in long-term care service provision, irrespective of the role of Medicaid. Part III focuses on the specific past, present and projected ICF-MR utilization. It also examines state considerations in future ICF-MR services use, exploring some of the ambivalences articulated by states as they weigh the costs and benefits to themselves and their service consumers of the various options under Medicaid. Part IV then summarizes the current status of Medicaid Home and Community-Based Services programs within the different states. It also discusses state perceptions of the strengths and limitations of that program. Part V examines the current status of persons with MR/RC in nursing homes and the implications of P.L.100-203, which requires states to review the appropriateness of those placements and the appropriateness of "active treatment" services provided. It reviews internal state initiatives for nursing home residents with MR/RC within state residential care systems as a whole. Part VI examines state use of Medicaid options other than Intermediate Care and "Medicaid waiver" services for persons with mental retardation and related conditions. It summarizes state perceptions of the benefits and limitations of the optional programs in meeting the needs of their state's citizens with MR/RC. The report concludes with a brief summary and comment section. It examines the congruence between state residential care and related services systems, state goals for these systems, and the requirements of the various Medicaid programs.

PART I: THE CONTEXT FOR PRESENT AND FUTURE STATE POLICY

Residential services for persons with mental retardation and related conditions have been undergoing significant changes in recent years. While numerous statistics will be presented later in this report that document these changes, it is instructive to look first at perceptions of state MR/DD agencies as they develop, regulate, and modify services for their citizens with mental retardation and related conditions.

Prevailing Principles Within the MR/DD Field

Residential and related services for persons with mental retardation and other developmental disabilities have been shaped in the past decade largely by a set of philosophical principles that have moved over time from ideals promoted by advocates, to predominant professional perspectives, to principles guiding the administration and organization of public programs. One of the most notable trends shaping services in recent years has been adoption of notions such as "normalization," "placement in the least restrictive environment," and "community integration" as formal objectives of state agencies administering services for persons with mental retardation and related conditions. Briefly, "normalization" asserts that the "treatment" of persons with mental retardation and related conditions must recognize and reflect that individual's dignity as a person, his/her natural membership in a native society and community, and his/her right to live as closely as possible in the manner of the culture. "Least restrictive environment" asserts that while making appropriate accommodations for basic health and safety, the preferred setting for a person is the one that offers the fewest restrictions on one's independence and the greatest opportunities to further one's independence. "Community integration" is a multi-faceted concept reflecting the value to people with developmental disabilities of sharing in community life. It involves at least four aspects, including, 1) physical integration: to be a member of a community one must live in that community; 2) cultural integration: to be a member of a community one must exhibit culturally valued lifestyles and roles; 3) social integration: to be a member of a community one must enjoy reciprocal interpersonal relationships with other community members; and 4) self-determination: to be a member of a community one must be able to affirm one's individuality

through expressions of personal independence and preference within the limits and according to the standards of the community. A few years ago these were organizing concepts for only a small number of the most "progressive" state MR/DD agencies. Today they are explicitly or implicitly recognized as important guiding principles by most state MR/DD agencies. They are also implicitly a part of the federal policy goals of independence, productivity, and integration articulated by Congress in the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987.

Research on Residential Services

The orientation of state residential programs is being influenced by research as well as philosophic principles. Recent years have brought dramatic increases in federal, state, and privately funded research on developmental outcomes, services, and experiences associated with different types of residential facilities. Research on developmental change associated with different residential settings has been increasingly evident and is an area of nearly universally acknowledged importance. There has been a growing focus documenting outcomes of residential programs. Particularly notable have been research projects monitoring the developmental change following community placement of persons involved in court ordered and monitored deinstitutionalization. Using this project's state survey, an effort was made to identify all unpublished, state sponsored studies of long-term developmental change associated with deinstitutionalization. These studies were added to the body of published research identified through traditional journal abstracts and computer searches. In all, 17 longitudinal studies of the outcomes of deinstitutionalization were identified as meeting the following specific minimal criteria: 1) it followed 6 or more individuals from public institution placements through at least six months of living in a community facility, with community facility defined as having 15 or fewer residents and being located off the grounds of a large facility; 2) it collected baseline data while persons were still in the institution; 3) it measured overall adaptive behavior (i.e., basic living skills) and/or specific types of adaptive behavior (e.g., self-care/domestic skills, communication skills, social skills) in the same manner and with the same instruments in both settings; 4) it reported basic demographic and diagnostic

information on institution and community facility subjects; and 5) it studied persons who were discharged to community-based facilities from institutions in or after 1975.

The results of 17 studies of developmental change associated with deinstitutionalization are illustrated in Tables A-1 and A-2 of Appendix A of this report. Table A-1 (experimental/contrast groups) shows the outcomes reported for studies in which changes in adaptive behavior for persons who moved to the community are compared with changes for persons of similar characteristics who remained in state institutions. The adaptive behavior (and problem behaviors where studied) of each group were measured both before and after the move. Table A-2 shows the outcomes reported in studies utilizing a longitudinal approach to measuring changes in adaptive behavior. These studies measured behavior before or at the time of deinstitutionalization and then at various times after the move. The analysis of all identifiable research meeting minimum standards, provides remarkably consistent evidence of the benefits of deinstitutionalization. Six of the seven experimental/contrast group studies reported statistically significant greater achievement in either overall adaptive behavior, or in the basic self-care/domestic skill domain for those who moved to community living arrangements relative to those who remain in state institutions. In the seventh study the community sample showed greater achievement in the self-care and domestic skills area, but the difference did not reach statistical significance. Among the longitudinal studies, 7 of the 10 reported statistically significant increases in overall adaptive behavior or in the basic self-care/domestic skill area after movement to the community. An eighth study would have most probably shown statistically significant changes, but no statistical tests were employed and the reported data did not permit such testing. The other two studies in this area showed positive behavior changes after movement to a community residence, but the changes were not statistically significant. Policymakers in many states are increasingly being made aware of and are responding to the strong and consistent findings that gains in personal development more rapidly accrue to people living in community settings rather than institutions.

Although individual states have responded somewhat differently to the generally prevailing principles shaping residential services systems for people with mental retardation and related conditions

and to the compelling research which supports these principles, there are notable similarities. State MR/DD agency mission statements, program principles, and residential service goals exemplify many of these similarities, and their review provides an instructive context for the examination of current and projected trends in Medicaid and related program utilization.

Before looking specifically at how these concepts are evident in the program principles of state MR/DD agencies, it may be useful to examine the basic responsibilities of state MR/DD agencies, as defined by state legislation and/or the state department within which the agency falls.

Basic Responsibilities of MR/DD Agencies

Residential services for people with mental retardation and related conditions are fully or substantially administered by state mental retardation/developmental disabilities agencies. While the activities and accomplishments of these agencies are often substantially affected by policies within other agencies (notably state Medicaid agencies and local government), the MR/DD agencies are seen as having the primary role in implementing and translating public commitments into programs and services for persons with mental retardation and other developmental disabilities.

Statements of basic programmatic responsibility and legislative authority of the mental retardation/developmental disabilities agencies were reviewed from the case study states. These policy statements reflected four broad recurring categories of responsibility given to these agencies. These general themes emerged regardless of the extent of actual authority vested in the agencies to fulfill the basic mission. The four recurring components of broad agency responsibility were:

- providing an adequate supply of residential services;
- providing residential services that are appropriate in relation to the needs of individuals with mental retardation and other developmental disabilities;
- promoting optimal efficiency in the use of state resources; and
- maintaining appropriate standards of quality in residential services programs.

Some state agencies have been given additional basic responsibilities. These range from rather concrete, fiscal responsibilities, such as to "assure maximum federal or private participation in the

delivery of services to Minnesotans with developmental disabilities" (Minnesota) to more programmatic responsibilities, such as to "assure such services are designed in a way that significantly increases the independence, productivity and integration of people with developmental disabilities" (Oregon).

Program Principles of State MR/DD Agencies

The distinction between the responsibilities of a state MR/DD agency and the expressed principles by which the program operates is largely that the former are given to the agency by a higher government authority (legislative and/or parent agency), while the latter are generally internally derived by agency personnel, often with participation of advisory groups. In an organizational sense the basic program principles of MR/DD agencies represent their ideals, however much they are constricted by factors seen as beyond the agency's direct control. Nine of the ten case study states provided written materials, usually state plans, which contained expression of the principles that the MR/DD agencies were using to guide their programs. To exemplify one such statement, the Colorado Division for Developmental Disabilities identified the following:

- to provide appropriate programs to persons with developmental disabilities throughout their lifetime regardless of their age or degree of handicap;
- to prohibit deprivation of liberty of persons with developmental disabilities, except when such deprivation is for the purpose of care and treatment and constitutes the least restrictive available alternative adequate to meet the person's needs, and to ensure that procedures governing placement and habilitation of such persons afford due process protections;
- to ensure the fullest measure of privacy, dignity, right, and privileges to persons with developmental disabilities;
- to ensure the provision of services to all persons with developmental disabilities on a state-wide basis;
- to enable persons with developmental disabilities to remain with their families and in their home communities;
- to promote socially and physically integrated community-based services for persons with developmental disabilities which reflect the patterns of everyday living;
- to encourage state and local agencies to provide a wide array of innovative and cost-effective services for persons with developmental disabilities; and
- to ensure that persons with developmental disabilities receive services which result in increased independence, productivity, and integration into the community.

There were a number of common themes among the published statements of principles of the MR/DD agencies, as was true with the statements of responsibilities. The values and commitments articulated by 5 of those 9 states are shown in Table 1. It should be noted that the numerical count of elements should not be used to compare states. Some states expressed their program principles in general terms from which one might easily infer a number of more specific "values." Such inferences have not been recorded. But the significance of these examples from the case study sample is to show the consistency of basic principles that are guiding MR/DD services in the U.S. today. It is important to realize that the elements of this basic list describe what most state MR/DD agencies are trying to accomplish as they administer basic federal and state policies and programs. As will be noted in each of the subsequent parts of this report, states cite many impediments to fully reflecting these principles within the existing policies and programs.

Service Goals for MR/DD Agencies

Despite substantial variations among the case study states, and among virtually all 51 states participating in our mail survey, it is clear that there is a strong, widespread and growing tendency for state MR/DD agencies to see their basic responsibilities and service goals in terms of the following:

- increasing community-based living opportunities and decreasing the number of persons in institutional care;
- increasing the flexibility available for responding to the specific needs of individuals;
- broadening the array of services and supports available to serve people who have widely ranging needs and life circumstances;
- improving the quality of both institutional and community services through increased technical assistance, personnel training, monitoring, and/or funding;
- increasing support to and involvement of families in the life of their member with mental retardation or related conditions;
- using and promoting policies to meet commitments, including promotion of Medicaid waiver use, active involvement in public policy debate in support of community services and support and promotion of federal Medicaid reform.

Table 1

Expressed Values and Commitments of Sampled State MR/DD Agencies

Values/Principles for Services to People with MR/DD	Case Study State								
	CA	CO	CT	FL	IN	MN	NY	OR	TX
Respect for rights and dignity			X	X	X	X		X	
Right to placement in least restrictive environment	X	X			X	X	X		
Preferability of normal(ized) community living	X	X	X	X	X	X	X	X	X
Services based on individual needs/ circumstances		X		X	X	X	X	X	X
Choice/self-determination of consumers		X	X	X	X	X		X	
Increase independence, productivity and/or integration		X	X	X	X	X	X	X	X
Preservation and support of family, permanency planning			X	X		X		X	X

An examination of the service goals of state MR/DD agencies today shows them to be much less often derived from the designated, relatively narrowly-defined or "value-free" responsibilities of the agency, and much more often derived from the kinds of program principles outlined in Table 1. Although by no means universal, a concluding statement in Florida's Five Year Service Plan (1988) is representative of the position of many states.

> Support and services to persons to allow them to live as independently as possible has become the goal of service provision. To direct this goal, guiding values and service principles have been developed. These principles concentrate on the fact that people who are developmentally disabled want the same things out of life that everyone does--family, friends, a home, work and recreation. Services will now be directed toward supporting people in community life. This will include family supports, supported living and supported work, all directed at helping people living in their own natural environments (p. 105).

PART II: GENERAL TRENDS IN RESIDENTIAL SERVICES

Four general trends are evident in the review of residential services for people with mental retardation and related conditions during the decade from 1977 to 1987:

- continued reduction in the use of large state institutions (down 37%);
- increased utilization of small facilities, i.e., those serving 15 or fewer individuals (up nearly 200%);
- decreased overall rates of residential placement as a proportion of the total population (down 9%), with stabilization since 1982; and
- particularly significant decreases in the rate of residential placement for children and youth, most dramatically in state institutions (down over 200%), but also in all types of residential placements (down 45%).

These trends are projected to continue over the next few years, based on information provided by state MR/DD agencies on their plans for residential services and the factors associated with these trends and projections.

This section describes trends and projections in the utilization of residential services in general, that is, without regard to whether those services are funded through Medicaid. It looks at residential services for the nation as a whole, as well as for individual states. In addition, attention is given to factors reported by states as being particularly influential in their recent patterns of residential services provision, as well as those expected to be significant influences on state projections over the next few years.

Deinstitutionalization

Deinstitutionalization has been and remains a social policy and program trend of continued importance in residential services for people with mental retardation and related conditions. Figure 1 shows the trend in average daily state institution populations since 1880, the year in which data were first gathered on a national basis. It shows populations of state institutions increasing steadily from 1880 to 1967, when they reached a high point of 194,650. In the subsequent 20 years the average daily population decreased by over 50% and more than 100,000 people to an average for Fiscal Year 1987 of 94,696.

Placements per 100,000 Population

Even more dramatic than the net decrease in state institution populations has been the decreasing rate of state institution placement (average daily population per 100,000 total U.S. population). In Fiscal Year 1987, the rate of placement in state institutions nationwide was 38.9 per 100,000. That rate was just 39% of the rate of placement in 1967 (98.6 persons per 100,000 of the general population).

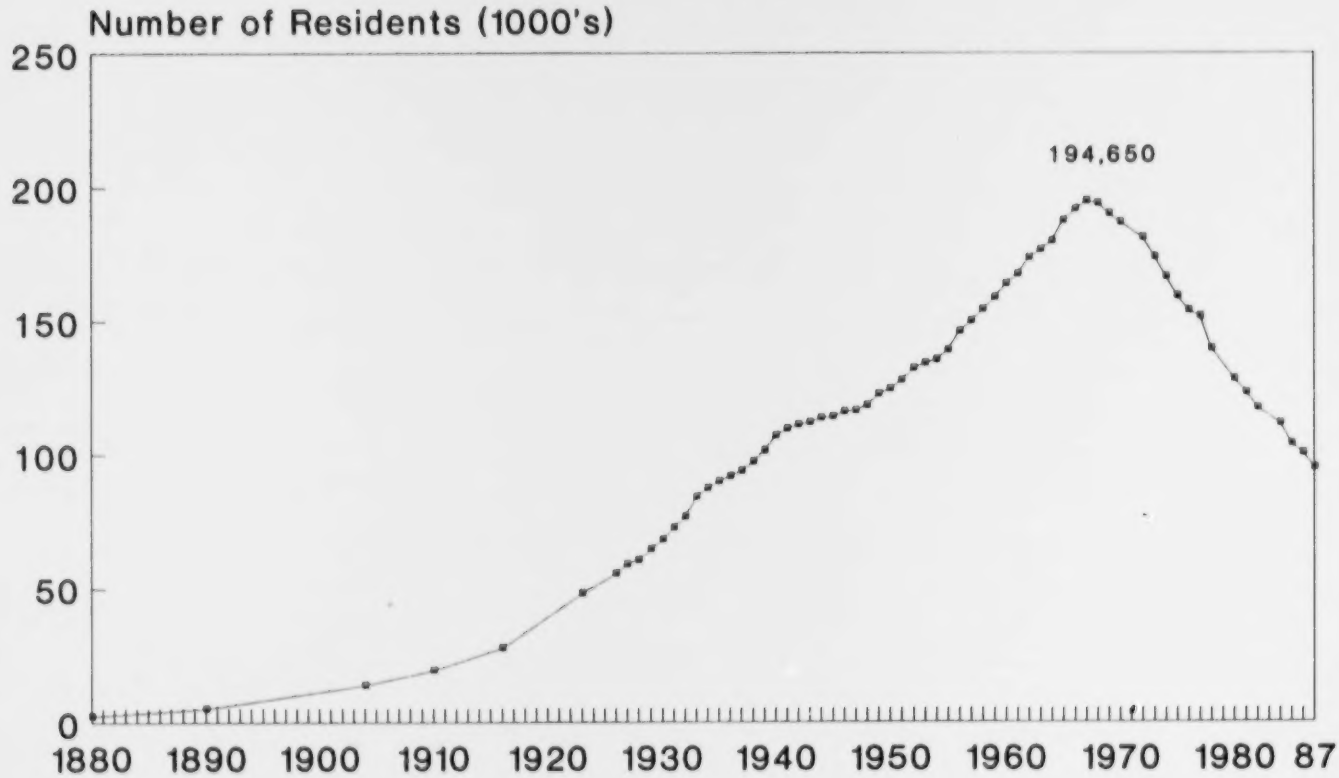
Movement Patterns in Deinstitutionalization

Two patterns have combined to create the decreasing populations in state institutions over the past two decades: rapidly decreasing total admissions and discharges which substantially outnumber admissions. Although discharges of persons from state institutions have been more commonly associated with the phenomenon of decreasing state institution populations, in reality greatly lower admissions to state institutions have actually contributed more to institutional depopulation than have institutional releases. From Fiscal Year 1967 to 1987 annual admissions to state institutions decreased from 14,904 to 5,398. Annual discharges actually decreased somewhat over the period from 11,665 to 8,049, although throughout the period discharges plus deaths in state institutions remained 4,000-6,000 more than admissions. In the 1980s alone admissions to state institutions decreased from 11,141 (in 1980) to 5,398 (in 1987).

Restricted Admissions

The two major factors in reduced admissions to state institutions are the unwillingness of most families to accept such placement as an option for out-of-home care and the concerted efforts of states to reduce total institution placements. A critically important and interrelated factor has been the development of community-based alternatives and the assumption that such placements will continue to grow. The restrictions of one form or another that most states have placed on admissions to large state-operated facilities have also been a significant factor. Among the 10 case study states, for example, all but Colorado and Oregon have developed formal policies to restrict admissions; and the two states without formal policies indicated that they have informal standards that serve to restrict

Figure 1
Total Average Daily Population of State Institutions for People with MR



admission to large state facilities. Nationwide, 34 of 51 states indicated specific restrictions on the "types" of people who can be admitted to state institutions. Restrictions are most frequently based on one or more of the following three factors: (1) restriction on all admissions except those through court action, either civil commitment or through criminal justice proceedings; (2) admission only of individuals with the most severe disabilities, including severe behavior disorders, or (3) admission only of persons above a certain age. For example, admissions to large state facilities in Indiana are limited to individuals with behavioral characteristics which are "currently unacceptable in the community (i.e., dangerous to self or others)," and the state envisions that services to such individuals will eventually be the sole purpose of their state MR/DD institutions.

There is growing consensus that adoptive or foster families, or family scale arrangements, are preferable for children and youth who cannot be maintained in their natural home. For example, a recently promulgated policy in Florida permits only court-ordered state facility admissions for children under the age of 16; there are no exceptions, even for emergencies. Minnesota prohibits admissions of children to state institutions and has only about 10 children and youth below 18 years still residing in its state institutions. Although children can still legally be admitted to state institutions in most states, the practice is becoming more and more rare. In 1965 there were 91,592 persons 21 years and younger in state institutions. By June 30, 1987 there were only 12,026 persons birth through 21 years in state institutions. Only 3,030 of these young people were below the age of 15. Indeed, 86% of the total decrease in state institution populations from 1965 to 1987 can be accounted for by the decrease in the number of persons between birth and 21 years.

Institution Closures

Related to the trends discussed above is the increasing tendency of states to close state institutions. In the survey of states four states reported at least 1 state institution closure during Fiscal Year 1987, with a total of 5 state institutions being closed altogether. States also reported actual or projected closures during Fiscal Years 1988, 1989, and 1990. Although the majority of states anticipated no closures over the period, a total of 13 states indicated a total of 20 state institutions were planned

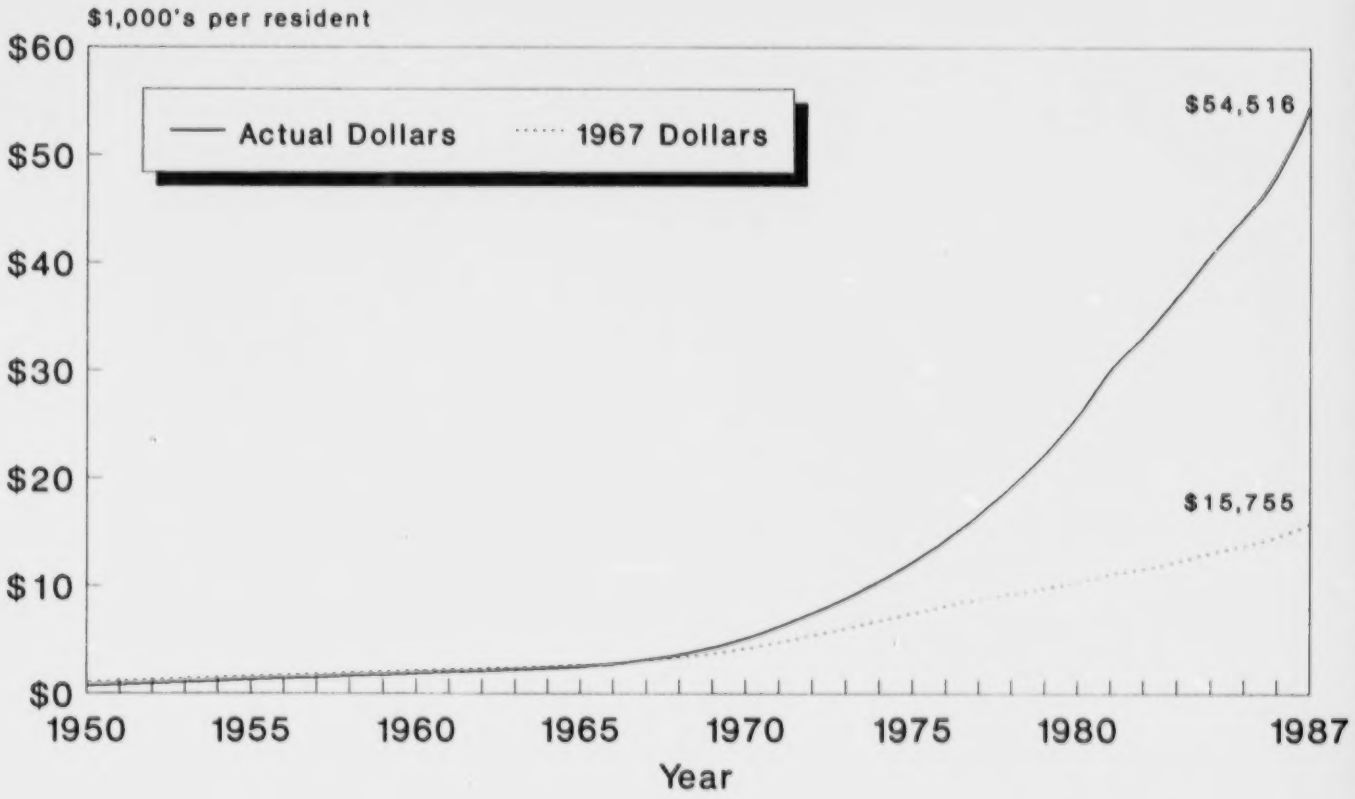
for closing during the June 30, 1987 to June 30, 1990 period. Institution closure is increasingly an issue in states as it becomes ever more evident that decreasing the populations of institutions remaining in operation simply spreads stable or increasing institutional administration and operations expenditures over fewer people unless whole institutions are closed. To exemplify the problem, among institutions which remained open from June 30, 1986 to June 30, 1987, average daily populations decreased 5.8%, while average cost per day went up 12.8% and total institutional costs increased 7.7%.

Cost Per Day of Care

The rapidly rising costs of institutional care clearly are of concern to states. From 1967 to 1987 the costs of state institution care increased dramatically (from $2,965 to $54,516 per resident). Even in dollars adjusted for changes in the Consumer Price Index over this period, costs of care in 1987 were over 5 times as great as in 1967. Figure 2 shows the trends in residential care costs in both actual and adjusted dollars ($1=1967) between 1950 and 1987. In terms of "real dollar" equivalents, the annual cost of care in state institutions for people with mental retardation increased from just over $1,000 to nearly $16,000 per resident over the 27 year period or a real dollar compounded growth of over 11% per person per year.

A number of factors have contributed to the increasing costs of residential care. One factor has already been noted: the spreading of fixed institution costs for administration, maintenance, housekeeping and so forth spread over fewer and fewer people. Another contributing factor has been the increasingly disabled population of persons served in state-operated facilities. In 1964, 40% of all residents of state-operated facilities for people with mental retardation were classified as having borderline, mild, or moderate mental retardation. By 1977, that proportion had decreased to 27%, and by 1987, only 17% of all residents were identified as having borderline, mild, or moderate retardation, i.e., 83% were classified as having severe or profound mental retardation. Associated with these changes have been increased intensity and specialization and, therefore, cost of professional and direct care staff.

Figure 2
Annual Cost of State Institutions for People with Mental Retardation



Other contributions to increasing costs have come from legislative and judicial efforts to upgrade the quality of living and of habilitation services. Finally, the ICF-MR program has brought considerably more demanding and costly program, staffing, and physical plant standards. It has also significantly cushioned the impact of rapidly increasing institution costs for the states through federal cost sharing, although since 1982 total state institution cost increases have been roughly proportional to increases in federal costs.

The move away from state institution care appears today to be both a stable trend and a largely irreversible one. The forestalling and foregoing of admissions to all but individuals with the most severe impairments, the rapid decrease of nonadults in residence, the rapidly increasing costs of institutional care, the strong evidence of foregone benefit to residents, reduced demand (i.e., the unwillingness of most parents to accept state institutional placement), and the evolution of the program principles and service goals among the state MR/DD agencies, as described above, are all operating to further reduce institutional populations.

Residential Services: Current Status, and Short-Term Trends

The total population in large state-operated mental retardation facilities and units on June 30, 1987 was 95,052. States also reported an additional 2,849 persons with a primary diagnosis of mental retardation in state-operated institutions other than mental retardation facilities (almost exclusively mental health facilities). Although the total number of persons with mental retardation in state mental retardation and psychiatric institutions is about the same as 50 years ago (96,696), residential services in general are obviously very different today. While small community-based facilities existed in the 1930s (Lakin, Bruininks, & Sigford, 1981), they made up an extremely small part of the available residential placements at that time. In contrast, on June 30, 1987 facilities of 15 and fewer residents had a greater total population of persons with mental retardation than did large state institutions (118,570 vs. 97,901).

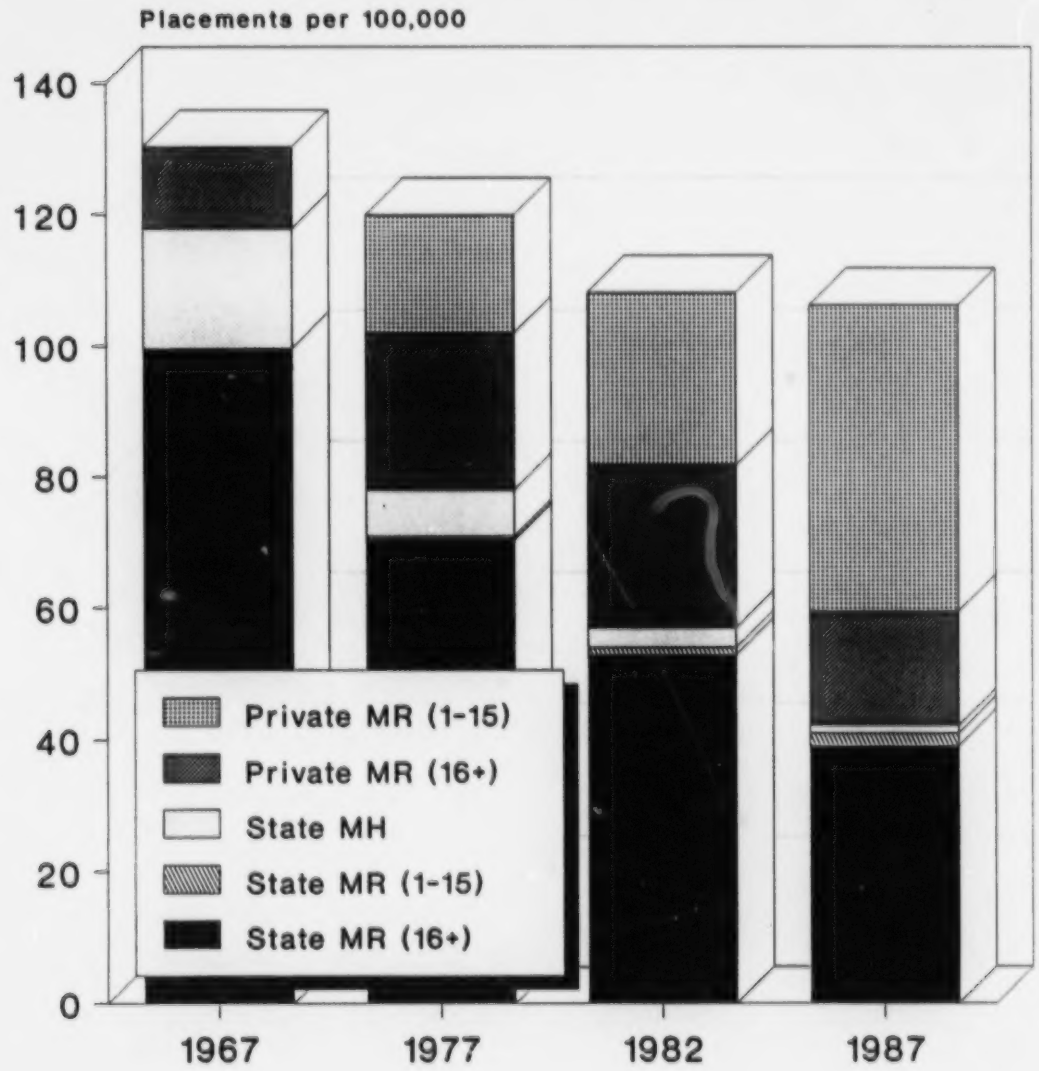
Placement Rates for Different Types of Facility

Figure 3 shows the number of persons with mental retardation in different forms of residential care per 100,000 of the general population in 1967, 1977, 1982, and 1987 for state mental retardation

institutions, for state mental health institutions, for small (1-15 residents) state-operated group homes, and for small and large (16+ residents) nonstate mental retardation facilities. (Size distinctions are not available for private facilities in 1967 and because most people were in large facilities, all facilities are shown in the 16 or more residents category.) Three significant trends are evident in Figure 3. The first is the dramatic decrease in the rate of placement into large public institutions (a trend that has already been discussed). The second is the increase in the rate of placement into small residential facilities for persons with mental retardation (a trend to be discussed subsequently). The third is the significant overall decrease in the rate of residential placement of persons with mental retardation since 1967. With respect to the third, in 1967, there were 130.3 persons in state institutions and nonstate mental retardation facilities per 100,000 of the general population. By 1977 the placement rate had decreased to 119.9, by 1982 to 108.2, and by 1987 to 106.3 per 100,000.

The most significant factor in this reduction has been the decreased number of children and youth residing in mental retardation facilities. Looking only at state and nonstate mental retardation facilities, data being unavailable on psychiatric facilities, the number of children and youth (0-21 years) in mental retardation facilities decreased from 91,100 in 1977 to an estimated 48,500 in 1986 (Taylor, Lakin, & Hill, in press). This represents a decrease in placement rate for children and youth from 42.1 to 20.1 per 100,000. Conversely, and importantly, the placement rate of adults (22 years and older) in mental retardation facilities actually increased between 1977 and 1987, from 72.4 per 100,000 in 1977 to 79.3 per 100,000 in 1982 to 85.2 per 100,000 in 1987. These data suggest rather convincingly that there has been little of the systematic "dumping" of people in need of support into unsupervised, nonlicensed settings to achieve deinstitutionalization goals. Overall the increase in placement of adults per 100,000 of the general population in mental retardation facilities reflects an increasing proportion of adults in the total population, increased longevity among adults with MR/RC in residential settings, and perhaps a decreasing number of facilities housing people with MR/RC that are not licensed or operated by state MR/DD agencies.

Figure 3
Placements per 100,000 U.S. Population by Type of Residential Facility



Recently there has been increased attention on the numbers of persons with MR/RC currently awaiting community-based residential services. This issue is addressed later in this report. However, with respect to discussion of residential placement rates, it must be noted that if current demand was met, the rate of placement of persons with MR/RC would be substantially higher than it is today. Unfortunately, current statistics on persons awaiting residential services have major limitations and statistics on persons awaiting residential services in past years are not available, except for state institutions.

Trends in Size of Facilities

Statistics that permit breakdown of the residential options in the various states by size and state/nonstate facility operation go back only to 1977. Despite the limited time period covered by available statistics (the ten years between 1977 and 1987), it is evident that there has been a significant increase in the use of small facilities for people with mental retardation and related conditions. In 1977 there were 40,424 persons with mental retardation in small (15 or fewer residents) residential facilities (16.3% of all residents). A total of 207,356 persons were in large (16 or more residents) facilities. By 1982, there were 63,703 residents in small facilities (26.1% of all residents) and 179,966 persons in large facilities. By 1987 there were 118,570 residents (46.4% of all state and nonstate facility residents) in small facilities. A total of 137,133 people were in large facilities. The actual reduction in the number of residents in large facilities in ten years between 1977 and 1987 was 34%, while the number of residents in small facilities increased by 193%.

Interstate Variability

Although national trends are reflected in data on patterns in state residential service utilization, there is considerable variation among the states. Table 2 provides a summary of the state-by-state and national distribution of residents of state-licensed, contracted, or operated mental retardation facilities on June 30, 1987. Statistics are provided for large and small mental retardation facilities that are operated by state agencies and by nonstate (private and local government) agencies. These statistics show major differences among states in their total number of residents in large and small, state and

nonstate facilities, as well as in percentage of residents in nonstate facilities, percentage of residents in facilities of 15 and fewer residents, and average number of residents per facility.

Percentage of residents in nonstate facilities. There has been very substantial growth in the number and proportion of nonstate residential programs for persons with mental retardation in recent years. This is an obvious and direct result of the nationwide movement from large institutions, where most people are in state facilities, to small, community-based settings, the vast majority of which are private. A related and potentially beneficial outcome of this shift is that today most people are in facilities that are operated by agencies other than the various state agencies with licensing, certification, and monitoring responsibility, reducing the potential for conflict of interest. On June 30, 1987, 61% of the residents in mental retardation facilities in the United States were in nonstate facilities, i.e., facilities operated by private agencies or, in some cases, by local governments. This compares with about 37% in 1977. Interstate variations were found to be large, with four states over 80% (Maine, New Hampshire, Alaska, and Minnesota) and six states below 35% (Virginia, Mississippi, Arkansas, South Carolina, Alabama, and Wyoming). A total of 37 states had more than half their residents in nonstate facilities on June 30, 1987.

Percentage of residents in small facilities. Accompanying the privatization of residential services for persons with mental retardation has been a rapid growth in the number of persons in relatively small facilities. Persons who are moved to private facilities from state facilities tend to go from large facilities to small facilities (nonstate facilities averaged only 4.7 residents on June 30, 1987). As noted above, only 16.3% of persons in mental retardation facilities resided in facilities of 15 or fewer residents on June 30, 1977. Ten years later (June 30, 1987), 46.4% of all residents were in small facilities. Despite such rapid change, a majority of persons with mental retardation in residential care were still in large facilities, with enormous variability among the states. On June 30, 1987, eight states had over 70% of their residents in small facilities (Alaska, Arizona, District of Columbia, Idaho, Michigan, Montana, New Hampshire, and Rhode Island). Just over half of all states (26) had reached the point at which more persons were in small residential facilities than were in large ones. On June 30, 1987

Table 2

State and Nonstate Mental Retardation Facilities and Residents, June 30, 1987

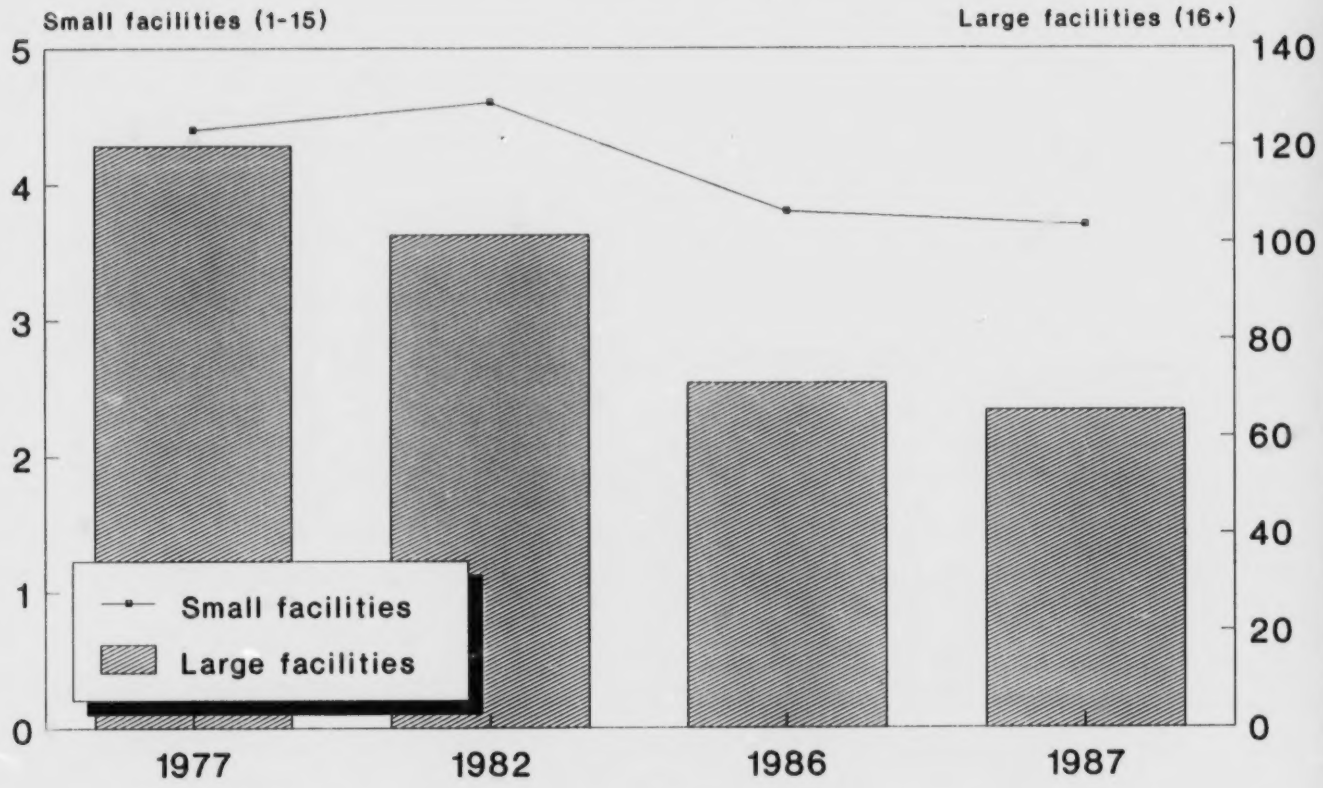
State	Facilities					Residents									
	Nonstate		State		Total Fac.	Nonstate			State			Total Res.	% Res. Priv.	% Res. in 15-	Ave. Res. per Fac.
	15-	16+	15-	16+		15-	16+	Total	15-	16+	Total				
ALABAMA	126	22	0	5	153	529	139	668	0	1,308	1,308	1,976	33.8%	26.8%	12.9
ALASKA	16	6	0	1	23	227	23	250	0	60	60	310	81.9%	73.2%	13.5
ARIZONA	43	0	19	3	65	1,225	0	1,225	134	49	183	2,316	52.9%	52.9%	35.6
ARKANSAS	42	2	0	2	46	1,666	134	1,800	0	1,317	1,317	3,117	57.7%	53.4%	67.8
CALIFORNIA	3,584	807	0	7	4,398	17,849	4,174	22,023	0	6,880	6,880	28,903	76.2%	61.8%	6.6
COLORADO	360	6	35	3	404	1,699	346	2,045	280	661	941	2,986	69.5%	61.8%	7.4
CONNECTICUT	624	4	54	13	695	2,053	86	2,139	383	2,678	2,681	4,820	44.4%	42.6%	6.9
DELAWARE	165	0	0	1	166	597	0	597	0	383	383	980	39.1%	39.1%	5.9
D.C.	180	0	0	1	181	731	0	731	0	258	258	989	26.1%	26.1%	5.5
FLORIDA	649	82	0	6	737	3,247	2,891	6,138	0	2,061	2,061	8,199	74.9%	39.6%	11.1
GEORGIA	630	5	0	8	640	1,542	138	1,680	0	2,089	2,089	3,769	55.4%	40.9%	5.9
HAWAII	434	0	1	1	436	673	0	673e	0	260	260	941e	72.4%	71.5%	2.2
IDAHO	220	2	0	1	223	673	58	1,031	0	263	263	1,294	79.7%	52.0%	5.8
ILLINOIS	965	99	0	13	1,077	3,021	5,989	9,010	0	4,344	4,344	13,354	67.5%	22.6%	12.4
INDIANA	644	2	0	6	652	2,251	865	3,116	0	3,340	3,340	6,456	48.3%	34.9%	9.9
IOWA	514	33	0	2	549	1,268	1,166	2,434e	0	1,047	1,047	3,481e	69.9%	36.4%	12.6
KANSAS	629	10	0	4	643	1,781	676	2,457	0	1,248	1,248	3,705	66.3%	48.1%	12.0
KENTUCKY	312	2e	0	3	321	1,430	213	1,643e	0	886	886	2,529e	65.0%	56.6%	13.2
LOUISIANA	408	25e	6	9	446	1,176	1,341	2,517	33	2,882	2,915	5,432	53.7%	46.3%	12.2
MAINE	370	11	2	2	394	1,280	278	1,558	22	293	315	1,873	83.2%	83.2%	4.8
MARYLAND	672	3	1	7	683	2,612	80	2,692	12	1,554	1,567	4,259	63.2%	63.2%	6.2
MASSACHUSETTS	966	16	3	7	1,012	3,718	83	3,801	24	3,367	3,391	7,192	52.9%	51.7%	7.1
MICHIGAN	1,213	7	0	8	1,228	5,506	675	6,181e	0	1,658	1,658	7,839e	78.8%	70.2%	6.4
MINNESOTA	1,211	54e	7	9	1,281	2,990	2,119	5,109e	28	1,671	1,699	6,808	69.0%	58.2%	5.3
MISSISSIPPI	33	5	28	5	71	135	605	740e	183	1,553	1,736	2,476e	70.1%	11.0%	34.9
MISSOURI	414	142	5	10	571	2,167	1,707	4,074	11	1,847	1,858	5,932	68.7%	36.9%	10.4
MONTANA	323	0	0	3	326	913	0	913	0	827	827	1,740	52.5%	52.5%	5.3
NEBRASKA	248	3	0	3	254	1,048	344	1,392	0	773	773	2,165	64.3%	48.4%	8.5
NEVADA	82	0	0	2	84	528	0	528	0	174	174	702	75.2%	75.2%	8.4
NEW HAMPSHIRE	249	1	0	6	256	631	21	652	0	590	590	1,242	52.5%	50.8%	4.9
NEW JERSEY	1,087	2	0	10	1,099	3,018	72	3,090	0	5,205	5,205	8,295	62.7%	36.4%	7.5
NEW MEXICO	142	0	0	2	144	902	0	902	0	500	500	1,402	64.3%	64.3%	9.7
NEW YORK	3,486	35	422	34	3,977	12,825	1,252	14,077	3,218	10,022	13,240	27,317	51.5%	47.0%	6.9
NORTH CAROLINA	291	9	0	5	305	1,229	541	1,770	0	2,720	2,720	4,490	60.6%	27.4%	14.7
NORTH DAKOTA	202	2	1	2	207	959	43	1,002	12	398	410	1,412	71.0%	68.0%	6.8
OHIO	1,019	102	0	14	1,155	4,438	3,960	8,398e	0	2,900	2,900	11,298e	74.3%	39.3%	9.8
OKLAHOMA	128	25	0	3	153	817	1,738	2,555	0	276	276	2,831	90.2%	28.9%	18.5
OREGON	278	11	0	3	292	1,666	331	1,997	0	1,176	1,176	3,173	63.0%	52.5%	10.9
PENNSYLVANIA	2,503	122	0	19	2,644	6,652	3,026	9,678	0	5,133	5,133	14,811	65.3%	45.1%	5.6
RHODE ISLAND	218	5	25	7	255	668	93	761	172	390	562	1,323	71.5%	64.2%	5.2
SOUTH CAROLINA	302	3	2	3	310	1,229	76	1,305	22	2,232	2,254	3,559	63.3%	36.8%	12.3
SOUTH DAKOTA	237	0	0	2	239	1,076	0	1,076	0	482	482	1,558	69.1%	69.1%	6.5
TENNESSEE	288	6	0	5	299	1,586	234	1,820	0	2,074	2,074	3,894	53.3%	40.7%	13.0
TEXAS	409	51	59	16	535	1,570	2,958	4,528	444	7,936	8,380	12,908	35.1%	12.2%	24.1
UTAH	189	9	0	1	199	560	581	1,141	0	554	554	1,695	67.3%	33.0%	8.5
VERMONT	188	0	0	1	189	381	0	381	0	196	196	577	66.0%	66.0%	3.1
VIRGINIA	83	3	0	5	91	754	108	862	0	2,970	2,970	3,832	77.5%	19.7%	42.1
WASHINGTON	968	48	0	6	1,022	2,726	1,013	3,739	0	1,810	1,810	5,549	67.4%	49.1%	5.4
WEST VIRGINIA	497	3	0	3	503	868	43	911e	0	480	480	1,391e	65.5%	62.4%	2.8
WISCONSIN	1,453	19	0	3	1,475	4,190	1,660	5,850	0	1,868	1,868	7,718	75.8%	71.7%	5.2
WYOMING	28	0	0	1	29	211	0	211	0	409	409	620	34.0%	34.0%	21.4
U.S. Total	31,188	1,809	632	288	33,917	113,854	42,081	155,935	4,716	95,052	99,768	255,703	61.0%	46.4%	7.5

three states had less than 20% of their residents in small facilities (Mississippi, Texas, and Virginia). But even the states with relatively high proportions of institutionalized populations are moving steadily toward community-based services. As noted by the Texas respondent in comparing Texas statistics with national statistics:

> The trend line in Texas shows continued growth in the number of persons in facilities of 15 or fewer residents. If one sums the number of persons served today [January 1989]. In 15-bed-or-less ICF/MR's, persons served by the HCBS waiver, and persons served in state-funded residences, Texas would have approximately 25% of their residents in small residences. The persons residing in residences of more than 15 beds is a decreasing number because of on-going reduction in the state school population. The ICF/MR program (6 beds-or-less facilities) and the HCBS program will continue to grow. Therefore, we expect the percentage of persons residing in facilities of 15 or fewer persons to continue upward.

Average number of residents per facility. Nationwide there has been a dramatic increase in the number of very small facilities since 1982, causing a rapid reduction in the average number of residents per facility. In 1977 there was an average of 22 persons per state licensed, contracted, or operated residential facility. By 1987 that average had decreased to 8. Although a limited portion of that decrease can be accounted for by the inclusion in the 1987 survey of supported living arrangements (less than 24 hour supervision), these decreases were primarily caused by two factors: 1) rapidly decreasing average population among a relatively stable number of large facilities, and 2) a rapidly increasing number of small facilities of a relatively stable average size. While the total number of facilities with 16 or more residents increased from 1,730 in 1977 to 2,097 in 1987, their total residents decreased from 207,363 to 137,133. Figure 4 shows changes in the average size of facilities since 1977. The average size of facilities with 16 or more residents decreased from 120 in 1977 to 65 in 1987. The average number of residents in small facilities decreased only from 4.3 to 3.7, but the total number of small facilities increased from 9,300 to 31,820, as shown in Figure 4. Interstate variations in average facility size were large, from over 30 residents in three states (Arkansas, Mississippi, and Virginia) to less than 5 residents in 13 states. While the national average number of residents per facility was 7.5, the average of the state averages was 10.0. This difference was the result of a tendency for the relatively large residential care systems to have a smaller average number of residents per facility.

Figure 4
Average Size of Large and Small Residential Facilities



Resident Characteristics

Table 3 presents statistics on selected characteristics of persons with mental retardation and related conditions from the 1987 National Medical Expenditure Survey (NMES). These characteristics are reviewed below by type of facility operation (private for profit, private nonprofit, government all facilities) and size (15 or fewer residents; 16 or more residents). It must be noted, however, that small facilities (15 or fewer residents) in the NMES, reflected the same underidentification obtained in the Inventory of Long-Term Care Places (ILTCP), which was its sample frame. In addition, the NMES excluded all facilities of fewer than 3 residents. The effects of these limitations on population estimates for small facilities is not known.

Resident diagnosis. Data from the NMES show major differences in the degree of impairment of persons with MR/RC in mental retardation facilities. Differences were greatest among residents of government facilities and private facilities, with the population of the former being considerably more severely impaired (57% being profoundly retarded as compared with 19% of private facility residents). Differences between government and private facilities were noted for both small and large facilities. In large government facilities 60% of the resident population was estimated to have profound retardation as compared with about 26% of large private facility residents. Among small facilities an estimated 12% of private facility residents and 26% of public facility residents were profoundly retarded. However, applying those estimates to state statistics on the total number of persons in small residential facilities in the United States would yield an estimated 16,000 persons with profound mental retardation living in community-based residential facilities in 1987. This represents an increase of an estimated nearly 10,000 persons with profound mental retardation in smaller, community-based facilities in just 5 years. This reflects a clear and growing trend nationwide to increase opportunities for community living for all persons with MR/RC, however severe their impairments may be.

Table 3 also indicates that the vast majority (99%) of persons residing in mental retardation facilities are indicated to have mental retardation. However, for 4% of the estimated population, "borderline" retardation, which is no longer generally nor technically considered to actually reflect mental

Table 3

Selected Characteristics of Residents with Mental Retardation and Related Conditions in Mental Retardation Facilities by Facility Size[1] and Type[2] in 1987[3]

	Private for Profit			Private NonProfit			Government			All Facilities		
	15- res. (21,712)	16+ res. (31,919)	Total (53,632)	15- res. (35,590)	16+ res. (30,237)	Total (65,827)	15- res. (7,633)	16+ res. (91,541)	Total (99,174)	15- res. (64,936)	16+ res. (153,697)	Total (218,633)
Age												
0-14	7.2	5.6	6.3	1.2	8.0	4.3	8.9	3.5	3.9	4.2	4.8	4.6
15-21	10.1	9.1	9.5	10.0	17.4	13.4	8.3	9.8	9.7	9.9	11.2	10.8
22-39	43.5	46.6	45.3	59.7	46.4	53.6	40.0	54.8	53.7	52.0	51.5	51.6
40-54	20.9	21.3	21.1	21.5	19.5	20.6	25.3	17.9	18.5	21.8	18.9	19.8
55-64	9.1	10.7	10.0	5.9	7.6	6.7	10.5	6.9	7.2	7.5	7.8	7.7
65+	9.1	6.7	7.7	1.6	1.1	1.4	7.0	7.0	7.0	4.8	5.8	5.5
Disabilities												
Mental Retardation Indicated												
Borderline	8.1	6.9	7.4	4.0	5.9	4.9	2.6	2.0	2.0	5.2	3.7	4.1
Mild	21.2	20.3	20.7	28.7	26.0	27.5	21.6	6.7	7.9	25.4	13.2	16.8
Moderate	31.4	24.5	27.3	34.4	25.1	30.2	17.4	11.4	11.9	31.4	16.7	21.0
Severe	25.6	18.0	21.0	20.2	17.5	19.0	32.7	20.2	21.1	23.5	19.2	20.5
Profound	11.1	28.6	21.6	12.5	23.6	17.6	25.5	59.5	56.9	13.6	46.3	36.7
Total	97.4	98.3	98.0	99.8	98.1	99.2	99.8	99.8	99.8	99.1	99.1	99.1
Not MR/Related Conditions												
Epilepsy only	1.7	1.5	1.6	.2	.8	.5	0.0	.2	.2	.7	.6	.6
Cerebral palsy only	.7	0.0	.3	0.0	1.0	.5	0.0	0.0	0.0	.2	.2	.2
Autism only	.2	0.0	.1	0.0	0.0	0.0	0.0	0.0	0.0	.1	0.0	0.0
Spina bifida only	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Multiple related conditions	0.0	.2	.1	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Total	2.6	1.7	2.1	.2	1.8	1.0	0.0	.2	.2	1.0	.8	.8
Activities of Daily Living												
Dressing												
No difficulty w/o help	56.3	50.0	53.1	67.7	59.0	63.7	57.1	27.3	29.6	62.6	38.4	45.6
Uses special equipment/no other assistance	0.2	0.0	0.1	0.0	0.2	0.1	0.8	0.0	0.1	0.2	0.0	0.1
Received assistance or supervision	43.5	49.1	46.8	32.3	40.8	36.2	42.1	72.7	70.4	37.2	61.5	54.3
Using the toilet												
No difficulty w/o help	81.6	70.5	75.0	90.1	75.9	83.5	79.8	51.7	53.9	86.0	60.4	68.1
Uses special equipment/no other assistance	0.2	0.2	0.2	0.3	0.0	0.2	0.8	0.1	0.2	0.4	0.1	0.2
Received assistance or supervision	16.3	20.2	18.6	8.4	18.9	13.2	12.5	32.2	30.6	11.5	27.0	22.4
Did not do at all	1.9	9.1	6.2	1.2	5.3	3.1	6.8	16.1	15.4	2.1	12.5	9.4
Walking across room												
No difficulty w/o help	89.3	76.2	81.5	94.0	82.5	88.7	83.4	66.0	67.4	91.2	71.4	77.3
Uses special equipment/no other assistance	1.0	1.2	1.1	0.7	1.8	1.2	1.9	1.2	1.3	0.9	1.3	1.2
Received assistance or supervision	5.7	8.5	7.4	3.9	6.4	5.0	8.5	11.3	11.1	5.0	9.8	8.4
Did not do at all	4.0	14.1	10.0	1.5	9.2	5.0	6.3	21.6	20.3	2.9	17.5	13.2
Medical Conditions												
Circulatory conditions[4]	15.1	13.2	14.0	10.5	8.6	9.6	12.4	9.9	10.1	12.2	10.3	10.9
Arthritis or rheumatism	7.1	3.4	4.9	3.8	4.7	4.2	5.3	4.6	4.7	5.1	4.4	4.6
Diabetes	0.9	3.6	2.5	2.2	1.8	2.0	4.7	1.6	1.8	2.0	2.0	2.0
Cancer	1.6	0.5	1.0	0.6	1.1	0.9	1.2	1.6	1.6	1.0	1.3	1.2
Frequent constipation	12.2	17.6	15.4	8.7	12.9	10.6	22.9	31.3	30.6	11.5	24.8	20.9
Obesity	15.0	14.9	14.9	14.5	12.9	13.7	18.4	11.4	12.0	15.1	12.4	13.2

[1] Facility size groupings based on number of "set up beds" in facility (or its mental retardation unit). Some facilities may be larger than the size of their mental retardation unit. Columns marked 15- res indicate facilities or mental retardation units with 15 or fewer "set up beds;" 16+ res indicates 16 or more "set up beds."
[2] "Government" facilities are primarily state-operated, but also includes a small number of county operated facilities. One 600 bed facility with a missing "owner" item was assumed to be a government operated facility.
[3] Data are from the National Medical Expenditure Survey.
[4] Includes present high blood pressure, hardening of the arteries or heart disease; or past stroke or heart attack.

retardation, has been indicated. Of the less than 1% of individuals in mental retardation facilities who were indicated not to be mentally retarded the most frequently noted condition was epilepsy, which is considered a condition related to mental retardation for the purposes of eligibility for the ICF-MR program, provided adaptive behavior limitations are also present.

Resident activities of daily living. Ability levels in performing activities of daily living (ADLs) are summarized in Table 3. They also show very substantial differences between residents of government-operated and private facilities, with ADL skill levels generally lower among the former. In the area of dressing about 30% of government facility residents and 27% of large government institutions were reported to be able to perform the activity with no difficulty and without assistance. The same was said for 53% of private for profit facility residents and 64% of private nonprofit facility residents. Relatively little difference was indicated between residents of small and large facilities of private for profit and private nonprofit operation in this ADL skill. Very substantial differences were found between small and large government facility residents (57% and 27%, respectively, reported to be able to dress with no difficulty and without assistance).

Similar general patterns were obtained in the area of toileting. Only an estimated 54% of government facility residents were independent in toileting as compared with 75% and 83% of private for profit and private nonprofit facility residents, respectively. Barely half (52%) of large government institution residents were reported to have independent toileting skills.

Differences in the abilities of residents of different types of facilities to walk across the room were less pronounced than in some of the other areas reported. The proportion of government facility, and particularly government institution, residents with substantial limitations was considerably greater than for residents of other facilities. About two-thirds of government facility residents were reported to be able to walk across a room without the aid of other people or equipment. This was substantially less than the 82% of private for-profit and 89% of private nonprofit facility residents reported to be completely independently able to walk across a room. Still 67% of residents of large government institutions and

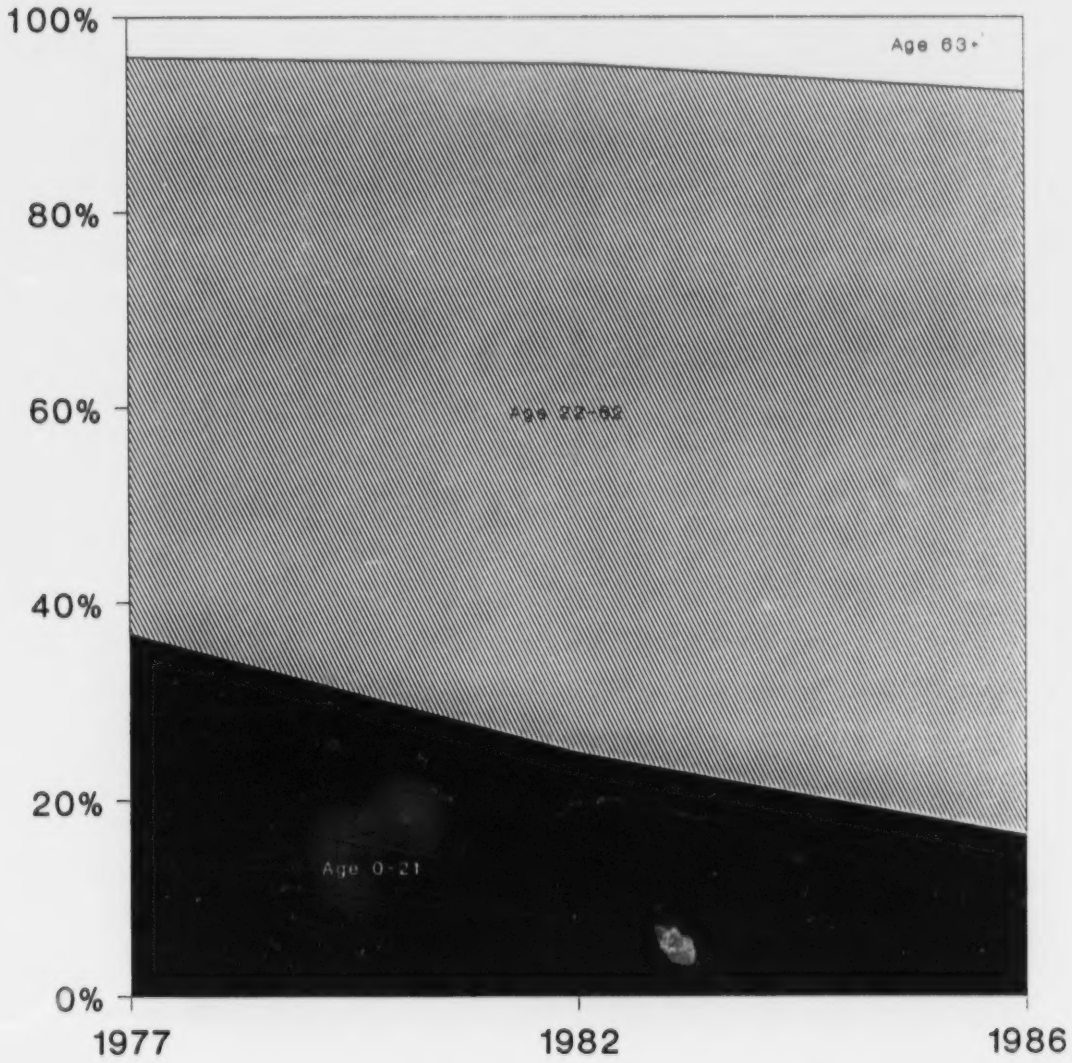
73% of residents of all large facilities were reported to be independent in their ability to cross a room without assistance from another person.

Medical conditions. The National Medical Expenditure Survey indicates few major differences among residents of various types of facilities in medical condition. Frequent constipation was reported for a higher proportion of residents in government facilities than private facilities and was particularly high (31%) among government institution residents.

Resident ages. As estimated by the 1987 National Medical Expenditure Survey, (NMES), the vast majority of persons with mental retardation and related conditions in mental retardation facilities are persons between 22 and 64 years old (79%). Age distributions are generally similar for private for profit, private nonprofit and government facilities. There was, however, a somewhat greater tendency of residents of private for profit facilities to be older than average and for residents of private nonprofit facilities to be younger than average. No substantial differences were noted in the ages of the residential populations of large and small facilities. The most notable statistic regarding resident age from the NMES was continuation of the dramatic decrease of children in out-of-home residential care. When compared with ages of residents with mental retardation obtained in the CRCS 1977 and 1982 census studies of all known public and private residential facilities, the NMES showed a continuing decrease in proportion and total of residents who were 14 years and younger between 1977, 1982 and 1987 (18.8% and 46,600 children [0-14 years] in 1977, 9.3% and 22,700 children in 1982, and 4.6% and 11,800 children in 1987).

Changes in resident ages. Earlier the dramatic decrease in the number of children and youth in state institutions from 91,600 in 1965 to 12,000 in 1987 was noted. While by no means as great there has been a parallel general decrease in the total number of children and youth (birth-21 years) in all forms of residential care. Figure 5 shows these trends using data from the 1977 and 1982 University of Minnesota census surveys of residential facilities and the 1986 Inventory of Long-Term Care Places. Minor adjustments were made to the ILTCP statistics because of its exclusion of several thousand specialized foster care settings included in the earlier University of Minnesota studies. These estimates

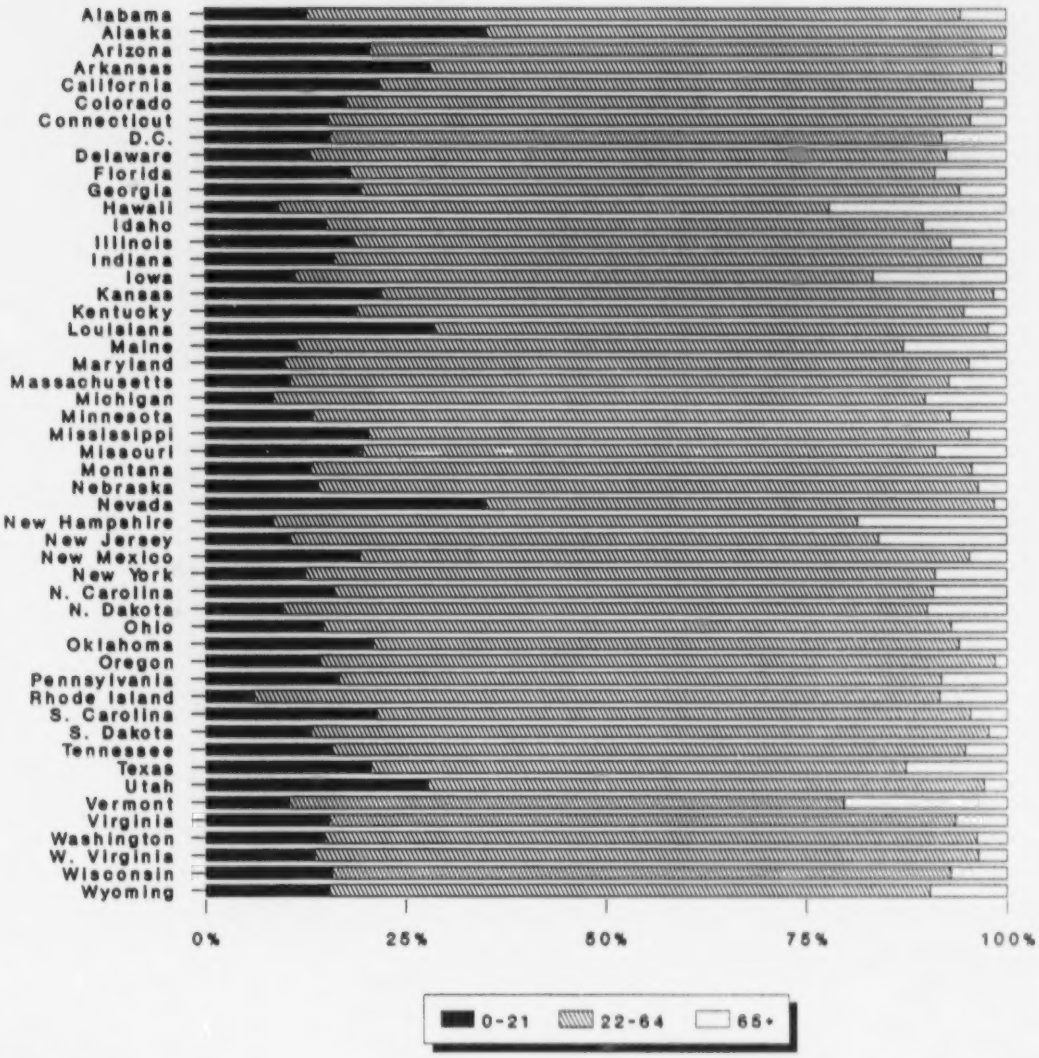
Figure 5
Percentage of Residents in Mental Retardation Facilities by Age



were based on the total number of such facilities states reported operating in 1986 and the data on the ages of residents in those facilities from the 1982 census survey. As can be seen from Figure 5, children and youth in residential facilities for persons with mental retardation decreased from 36.8% of all residents (about 91,000) in 1977 to 24.8% of all residents (60,000) in 1982 to 16.4% of all residents (48,500) in 1986. This represents a remarkable societal accomplishment, most directly attributable undoubtedly to the implementation of the Education for All Handicapped Children Act of 1975. This legislation not only assured educational opportunities to children in their local communities, but also communicated and reinforced a societal vision of children with handicaps as natural members of the communities into which they were born.

Interstate variations in resident ages. States differ substantially in the proportion of their residential populations made up of persons in three basic segments of the life cycle. Figure 6 shows interstate variations in the proportion of total residents who were children and youth (0-21 years), non-elderly adults (22-64 years) and elderly adults (65+ years). There is a limitation in the data in Figure 6 that must be pointed out before the findings are presented. These statistics are from facilities on the ILTCP that were serving primarily persons with mental retardation. In some states many of these facilities house persons with more than one disability. The ILTCP gathered age data on all residents of designated mental retardation facilities, including those who were not mentally retarded. This has a particularly notable effect on statistics regarding the proportion of elderly residents from states like Hawaii, Vermont and New Hampshire, which have traditions of board and care facilities serving more than one group of persons with disabilities, including frail elderly persons. Despite these limitations Figure 6 gives a generally good picture of the different large distributions of residents of facilities serving primarily persons with mental retardation in the various states. In all but 2 states (Alaska and Nevada), two-thirds or more of facility residents are persons within the productive adult years. Only eleven states had more than 20% of their mental retardation facility populations made up of persons 21 years or younger. This compared with 36 states in 1982 which had 20% or more of their residential population made up of children and youth 21 years or younger. Ten states had 10% or more of the residential

Figure 6
Age of Residents of Mental Retardation Facilities by State in 1986



population of their mental retardation facilities made up of persons who were 65 years or older. Completely comparable 1982 statistics do not exist because the earlier University of Minnesota survey acquired age data only on the residents with mental retardation and not all residents. In 1982, 3 states (Hawaii, New Jersey, Vermont) had about 11% of their residential population of persons with mental retardation made up of elderly persons (63+ years).

In summary, the residential population is aging. It is overwhelmingly an adult population. In most states children and youth make up a small and decreasing proportion of total residents; elderly people make up a small, but steadily increasing proportion of all residents.

Projected Changes in Residential Populations and Placements, June 30, 1987 to June 30, 1990

Changing Patterns Nationally

The state survey conducted in 1988 asked respondents from all states and the District of Columbia to project changes in their state's residential care system from June 1987 to June 1990. The primary limitation of these projections is their variability as to status in the planning process, with some representing actual program targets and others more as "educated guesses." A number of states projected changes within ranges. In these states the mid-point of the range was used as the 1990 projection. Figure 7 shows the summed national projections derived from the individual states.

In general, state projections showed a continuation of the trends described in this report, although at a slightly slower pace. State institutions were projected to experience steadily decreasing populations from 95,052 on June 30, 1987 (37.2% of all residents) to 83,334 (31.4% of all residents) on June 30, 1990. Growth in the number of people in small facilities from 1987 to 1990 was projected to be from a total of 118,570 to 141,027. The 1990 projection includes 135,182 persons in small nonstate facilities (50.9% of all residents) and 5,845 persons in state-operated small facilities (2.2% of all residents). About 57% of the increase in small facilities reflects transferred capacity from state institutions and large private facilities (projected to decrease from 42,081 to 40,986) to community

settings. The remainder of the projected increase in persons residing in small facilities (43%) would be the result of the projected 9,600 new placements being added to residential care systems in the various states during the 1987 to 1990 period.

State-by-State Projections, 1987-1990

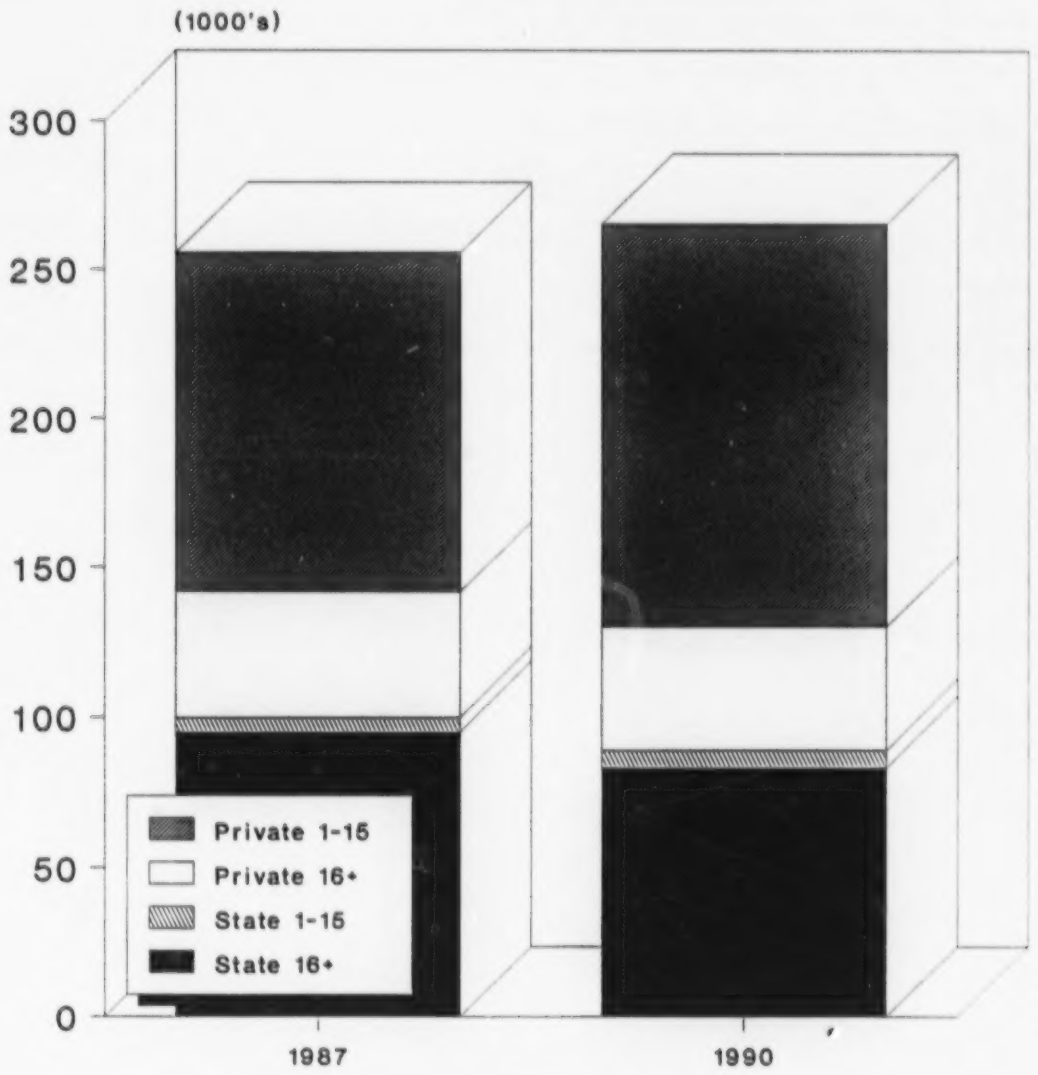
State projections of changes in their residential care systems between June 30, 1987 and June 30, 1990 showed considerable interstate variation in deinstitutionalization, facility size, and privatization, as described below.

Large state facilities. Stable or declining numbers of persons in large state-operated facilities were projected for the 1987 to 1990 period by all but three of the 51 states surveyed. The states of Rhode Island, West Virginia, Hawaii and New Hampshire projected the most dramatic decreases in the number of persons served in large state-operated facilities, with projected decreases of 50% or more. The number of residents in large state-operated facilities is not expected to change appreciably in six states. Increases of five percent to eight percent were projected by California and Missouri. Both of these states cited the anticipated pressure to discharge persons with mental retardation and related conditions from nursing homes under the OBRA-1987 (P.L. 100-203) requirements as the key factor.

Small state facilities. The majority (33) of states expect to continue to operate without small state-operated facilities in June 1990. Of the 15 states that currently have small state-operated facilities, Massachusetts and Missouri project the greatest increase (ten- and six-fold increases, respectively). Three states noted plans to begin utilizing small state-operated facilities for the first time between 1987 and 1990. They were Alabama, Kansas, and West Virginia, with plans to serve 60, 180, and 40 residents respectively in such facilities.

Large nonstate facilities. Large nonstate facilities, include facilities of 16 or more total residents operated by private non-profit, private for profit, or local government agencies. The latter have a limited role in a few states, most notably Ohio and Iowa. They do serve substantial numbers of people in those states. Nine states do not utilize large nonstate facilities and have no plans for future development. Most states (39) with large nonstate facilities project stable or declining numbers of persons in large

Figure 7
Current and Projected Distribution of Residents by Facility Size and Operator



nonstate MR/DD facilities. Two states (Alabama and Rhode Island) project elimination of existing large nonstate programs over the period. Three states project an increase in the number of persons residing in large nonstate facilities, with Indiana projecting an increase of 400 residents and Arkansas an increase of 60 residents. In Indiana's case the increase reflects primarily the conversion of existing Skilled Nursing Facility (SNF) and ICF-certified nursing home "beds" to ICF-MR certified beds. Arkansas's increase reflects the development of a single new facility for 60 residents.

Small nonstate facilities. Small nonstate facilities are most typically operated by private non-profit organizations, and may include so-called "group homes" and supervised semi-independent living arrangements as well as more structured or medically oriented small facilities. All but one state surveyed projected an increase in the number of residents of small nonstate facilities. Kentucky projected no change in small nonstate facility populations (nor in any other category of residential facility). States projecting the most significant increases in the use of small nonstate facilities included Arkansas, Connecticut, Illinois, North Carolina, Utah, and West Virginia, each reporting an increase of 50 percent or more.

Factors Affecting Trends and Projections

Several factors have been influential in state decisions to depopulate their large state institutions and to expand the availability of smaller units in the community between 1982 and 1987. In both the survey of all states and the 10 case studies, state respondents were asked about factors influencing the trends in residential services noted above. Although states were generally clear that the trends noted were part of a more universal movement toward community services, within each state particular factors or events were identified which gave shape or impetus to the state's evolving patterns of residential care.

External Factors Affecting Trends/Projections

Factors external to state mental retardation/developmental disabilities agencies or to state governments are a significant influence on the residential services system in most states. External factors noted by states as substantially affecting their residential and related services programs included

court actions, "look behinds" and other program monitoring activities of the Health Care Financing Administration, availability of the Home and Community-based Services waiver, and the generally increased demand for residential services within the state. Five of the ten case study states identified an external factor as the most significant influence on the state's residential service system between 1982 and 1987. Similarly 21 states in the national survey indicated that external factors were among the most significant factors affecting the state's projections for residential services by June 30, 1990.

Litigation. Litigation, generally leading to consent decrees requiring improvements in the state institutions, was noted as a significant factor in efforts to depopulate state institutions in a number of case study states (Connecticut, Florida, Minnesota, and Texas). Litigation was considered the most significant influence in Connecticut, Florida and Texas. A total of 16 states also noted in the state survey that the effects of litigation were major factors in their projected reductions of state institution populations. Those 16 states had a median projected decrease of 20% in state institution populations between 1987 and 1990, more than double the projected depopulation in states not citing litigation as a key factor. Although consent decrees have tended to focus on institutional conditions, they frequently include provisions regarding the number of and/or characteristics of clients for whom the institutional placement is considered appropriate. Such population related provisions have caused considerable resident movement from the institution to smaller facilities in the community. In other instances states have been required to improve staffing ratios in the state facilities, which they accomplished by depopulation as well as by hiring additional staff.

Federal oversight and requirements. Oversight by the Health Care Financing Administration (HCFA), in particular the federal "look behind" reviews, has been seen as a factor in stimulating depopulation of large state institutions and expanding the availability of community alternatives as part of state efforts to improve quality of care. Indiana's agreement with HCFA to reduce the use of nursing homes for non-elderly individuals with mental retardation and other developmental disabilities not in need of 24-hour nursing services and its plans of correction following HCFA's "look behind" review of state facilities are seen as the major influence on its residential services program over the past few years.

Among case study states "look behinds" were reported to be particularly significant in Colorado and Oregon, and were noted as a factor of influence in all but one of the ten states (California). Expectedly states were considerably less likely to associate federal oversight as a major factor in the projected future trends within their residential care systems, although 5 states did so.

An issue within the domain of federal requirements that will have great importance to states as they look toward 1990 will be requirements to review the placements of Medicaid certified nursing home residents with mental retardation and related conditions for appropriateness, as required by the Omnibus Budget Reconciliation Act of 1987 (P.L.100-203). An estimated 30,000 to 40,000 nursing home residents with mental retardation in Medicaid certified nursing homes seems reasonably reliable (see Part V). States also express considerable concern about the HCFA standards for "active treatment" required for persons remaining in nursing homes, as well as those who are residing in ICF-MR certified facilities. These concerns are discussed in Part III, "Intermediate Care Facilities for the Mentally Retarded (ICF-MR): Current Status and Short-Term Trends."

Increasing demand. Increased demand for residential services, and noninstitutional services more specifically, has been a major factor affecting several states. States responded to the increasing demand for services in significant ways between June 30, 1982 and June 30, 1987, creating a total of approximately 12,000 new residential placements; the overwhelming majority of these have been in facilities serving 15 or fewer individuals. Between June 30, 1987 and June 30, 1990, states project adding another 9,800 "beds" to their residential care systems. Increased demand for residential services for people living with their families is reported as a significant factor stimulating recent increases in community facilities in a number of states (e.g., New York). The net effect of this demand, however, has varied considerably from state to state. For example, in Mississippi the increased pressure from families for alternatives to state institutional care is considered the most significant influence in the 40 bed increase in the state's community facilities from 1982 to 1987 (277 to 317 residents), but in reality the change was small, as is the projected change to 1990. In some states (e.g., California and Florida) increased demand is reported to be exacerbated by general population growth such that significant

increases in residential capacity are barely able or are unable to keep up with demand. The general issue of meeting unmet demand for services is discussed at greater length later in this report under the heading, "Major problems in residential services."

The Medicaid Home and Community-Based Services Waiver. The availability of the Home and Community-based Services Waiver has been a significant factor in many states. Four of the ten case study states (Colorado, Connecticut, Minnesota and Oregon) identified the waiver's availability as one of the significant influences on the state's recent residential services system development. The waiver was also identified by 15 states in the state survey as an important factor in their projected future development of residential services.

Internal Factors

A number of the states emphasized agency or state government related factors as being particularly important to the evolving patterns of residential and related services for persons with mental retardation and related conditions. Certain of these, notably utilization of the Medicaid Home and Community-based Services waiver option, reflected "internal" decisions to access external support.

State policy. Although only one of the case study states indicated that the most significant factor influencing the residential service system 1982-1987 was a factor internal to state government (a state policy decision), all the case study states described various state actions that were major influences during that period. States are demonstrating increasingly proactive efforts to shape, not merely manage and monitor their residential care systems. The importance of state policy in the development of residential services is reflected in 46 states responding that formal agency goals and plans were among the primary factors affecting the projected changes in their systems between 1987 and 1990. In most of the case study states, specific policies were noted to reduce use of large institutions and expand use of small community residential alternatives. State policies in Colorado, coupled with the broad based consensus on policies and strategies for implementation throughout the public and private sectors, were reported to have been the strongest influence on the state's residential service system. Similar effects of state policies were also noted in California, Connecticut, Florida,

Minnesota, Mississippi, and New York. State policy activities that were considered influential on the various state residential services systems included regulatory actions, fiscal incentives for certain types of services, decisions to maximize FFP, and service system conceptual and organization modifications, including development of alternatives to residential facility-based models of service and support, and direct family support services.

Regulatory policies were reported to have been influential in several states, in particular restriction on the development of new ICF-MR facilities. Minnesota imposed a total moratorium on ICF-MR development until 1988 when 150 new community "beds" were authorized; Mississippi has been under an overall moratorium on long-term care facility development. More frequently, however, states have placed limits on the size of ICF-MR (or other residential facilities) that can be developed, such as six-bed limits in Connecticut, Florida, and Texas, and a five-bed limit in Oregon.

Fiscal incentives for the development of community alternatives have also been a factor in several states. Minnesota revised its regulations to remove a cap on rates for certain community facilities to provide incentives for placement of clients with more severe disabilities. Texas developed its Prospective Payment Program to stimulate placement of state institution residents in community settings by providing local mental retardation authorities with additional resources. Local authorities receive $55.60 per day in state funds per state institution resident returned to their area; the local agency can use the funds as needed for community service development and implementation. But several states note that generally low reimbursement rates to nonstate providers remains a strong disincentive to the expansion of community residential alternatives in some states. For example, the delays in obtaining a rate increase for private providers was a major factor in slowing down such expansion in California; recent (1988) passage of legislation carrying a rate increase is expected to encourage expansion of private residentiai facilities.

The decision to maximize FFP has been a significant factor in several states, including ICF-MR certification of residential services facilities, use of the Home and Community-based Services Waiver to support expanded services development in the community, and the use of certain other Medicaid

optional services for people with mental retardation and related conditions. Although expanded FFP is counter-balanced in some states (e.g., Indiana and Mississippi among the case study states) by concerns regarding an expanded obligation for the non-federal match, nearly all states seek to retain FFP at least at current levels, for example, by avoiding ICF-MR decertification of state institutions, by concentrating depopulation of state facilities to noncertified units, by balancing decreases in ICF-MR capacity with increasing Medicaid waiver utilization and other strategies.

Expanded alternatives to the residential facility-based model of services were seen by some states as affecting residential patterns. Increasingly state service systems include the availability of a range of options, with the emphasis on meeting the needs of individual clients. However, states differ greatly in the degree to which alternatives to residential facility placements are available. Several of the case study states discussed efforts to develop and expand "client-centered" residential supports, in which the state defines its role as helping a client find his or her own home in the community and then bringing needed services to the home of the client. This differs substantially from the traditional approach of bringing the client to residential facilities operated under state auspices. In Colorado, for example, the state has used its Medicaid waiver to develop the Personal Care Alternatives program. The program's three models have varied staffing to meet individual needs, including host homes, peer companions, and independent apartments. In the peer companion and independent apartment models the individual with a developmental disability lives with a disabled or non-disabled person and receives the degree of support services considered necessary for him/her to maintain residence in the community. The program is being used by individuals with severe as well as mild and moderate levels of disability.

Providing family supports is increasingly emphasized by the states and is seen as an influence on the residential service system. Family supports include services such as respite care, in-home services, transportation services, medical services, and parent training in ways to enhance their child's development. Some states also provide payments (subsidies) to families which can be used to defray the costs of maintaining a person with developmental disabilities in the home (e.g., to purchase special

equipment). Respite care, provided both in the family home by a respite caregiver and out of the home, is available in most states, at least on a limited basis, including all ten of the case study states. However, most of the states note that it is insufficient to meet the demand. Respite care was considered the most significant support to families in relation to reducing or delaying demand for residential services in four of the ten states (California, Florida, Indiana, and Minnesota).

Providing cash subsidies to families is a program being experimented with in a growing number of states. Among the case study states there was a $50,000 pilot project in Connecticut serving 18 families, a $2,000,000 state-funded program in Texas, and a $1,000,000 program serving 410 families in Minnesota. Florida has developed the Family Placement Program as an alternative to direct cash subsidies. The program includes a contract with a designated "caretaker" (parent, guardian, advocate or other interested adult) who receives money from the state to be used in accord with the specialized needs of the individual with developmental disability. Like many family support programs, however, the number served with existing resources, in this case, 260 individuals, is virtually insignificant in comparison to the number served in residential care (approximately 8,200 in Florida overall).

With the exception of family supports funded through the Home and Community-based Services Waiver and, in a few cases, other optional services under the Medicaid program, the overwhelming majority of family support and alternative services are funded with 100% state and local funds. Despite the growing interest in family supports among state legislatures and state government agencies, the competition for state resources appears to be a factor in the relatively small expenditure for these programs, especially when compared to the funding of residential services. Indeed, given the press for funds to meet basic needs, current goals for residential programs, and a lack of evidence that family supports and subsidies can be targeted so that actual deferred residential costs are equal to or greater than family support/subsidy costs, states are likely to be conservative in expanding their family support programs.

Various related programs, not typically seen as family support services, were also identified as significant in reducing demand for out-of-home placement, including the availability of public special

education and day programs for people living at home (Mississippi and New York). Case management of individuals living at home was also seen as reducing or delaying demand for residential services by facilitating access to alternate services (Colorado).

Major Problems in Residential Services

Two overriding and interrelated problems facing state residential care systems at the present time are rapidly increasing expenditures and increasing waiting lists. Each of these is in turn related to a number of other significant problems facing states, as illustrated by the case study states.

Increasing expenditures. Financing issues are a major factor affecting the development of residential services. All ten of the case study states noted they had insufficient resources to expand the residential service system enough to meet demand and/or to develop some of the kinds of residential services that they would like to make available (e.g., new small units in the community to serve medically fragile individuals presently served only in institutional settings).

Reimbursement rates to nonstate community residential providers were noted as a significant problem in the period from 1982-1987 in five of the ten case study states (California, Colorado, Minnesota, Oregon, and Texas). The most common effect of insufficient reimbursement funds was a reduction in the rate of community facility expansion, as providers felt that the available reimbursement rates lagged behind increased costs (California, Texas). In particular there was a sense that resource allocations for community services are not keeping pace with the increasing needs of people receiving and/or needing community living opportunities (Colorado, Minnesota, Oregon). In Minnesota providers were reported to be reluctant to accept clients with more challenging disabilities until a cap on reimbursement rates was removed. States also note the translation of inadequate reimbursement to specific program and personnel problems, notably low wages, which in turn negatively affects the qualifications and turnover of direct-care staff.

The fiscal constraints imposed by state budgets have been associated with some difficult choices for state policymakers. In states with extensive demand for additional residential services, the limits on state resources are perceived to have compelled choices between quantity and quality. In

particular the desire to improve quality by reducing average facility size and by increasing the array of individualized alternatives has been compromised by the press to provide more community residential placements. Some states have faced particularly difficult resource allocation questions because of the need to upgrade conditions in large state institutions in order to retain ICF-MR certification. Other states feel they have been reasonably successful in balancing their interest in expanded FFP with the need to hold down state expenditures, especially through greater participation in Medicaid options to ICF-MR (Colorado, New York). In a number of states the state legislature participates actively in line item decisions about the state budget for residential services, including the actual number of residential care placements that will be funded (e.g., Indiana, Minnesota), which sometimes makes long-term planning difficult. In Minnesota, the response of the Department of Human Services most recently has been to seek and receive legislative approval of a specific long-term proposal for residential and community services, including a very substantial reduction of state institution populations from about 1,450 in 1988 to about 100 in 1995. The plan, approved in 1989, contains specific numbers for the development of private and state-operated group homes and daytime habilitation programs.

Waiting lists. Waiting lists have continued to place pressure on states to expand their supply of residential services. All but two of the case study states (California, and Connecticut) have formal waiting lists for residential services, but even they acknowledge existing need for expanded community residential placements. Six of the ten case study states report waiting lists of 1,000 persons or more for residential services and that their lists are growing (Colorado, Florida, Indiana, Mississippi, New York and Oregon). Waiting lists in most states focus on the need for residential services in the community, either for people currently in institutions or for people already residing in the community. These "community" waiting lists are also reflected in a recent national estimate of persons waiting for community living arrangements produced by the Association for Retarded Citizens (ARC)-United States (Davis, 1987). While a number of limitations might be cited in this compilation of "best available statistics" (aggregated reports provided by each state affiliate), the ARC estimate that there are about

60,000 people nationwide waiting for some form of community residential services clearly indicates that the serious problems with unmet need in the case study states are by no means unique to them.

Based on case study states it appears clear that the waiting list issue is complex; available statistics do not generally permit separation of persons in the system awaiting improved services (i.e., in most states, residents of state institutions waiting for community services); persons in non-MR/DD long-term care awaiting placement in the MR/DD system (i.e., in most states, people in nursing homes awaiting placement in MR/DD settings); and people living with their families awaiting initial entry into a residential service setting. Based on the case studies, the state surveys and the data reported in Part V, each of these groups could contain 20,000 or more people nationwide.

Furthermore, the pressures for new long-term care capacity are seen as increasing. States note increasing numbers of young adults completing their schooling who now await services (Oregon, Minnesota). They also report that a factor of growing significance in the need for increased capacity is the aging of parents who have maintained their developmentally disabled family member at home for several years and are seeking residential placement for the first time (Colorado, Florida, New York). A related factor in many areas of the country is a lack of vocational and habilitation services for adults at home who have graduated from special education programs, but who along with their families are without access to developmental services or the "respite care" afforded parents by day programs (Indiana, Minnesota). In some cases it was noted that families have sought residential placement as the only way of gaining access to adult services. It is in this context of insufficient funds, long waiting lists for community services and goals and objectives that are shifting away from a facility focus to an individual consumer focus in which states make decisions about utilization of the various options available in the Medicaid program for providing services to persons with mental retardation and related conditions.

PART III: INTERMEDIATE CARE FACILITIES FOR THE MENTALLY RETARDED (ICF-MR): CURRENT STATUS AND SHORT-TERM TRENDS

The Intermediate Care Facilities for the Mentally Retarded (ICF-MR) program is an optional Medicaid service. It is by far the largest source of federal funding for residential services provided to people with mental retardation and related conditions. The ICF-MR program is currently used by all states to finance care in large state institutions. It is also used in virtually all states, although to varying degrees, to finance residential services in large nonstate facilities and/or in facilities with 15 or fewer residents.

State use of the ICF-MR program has generally been characterized by four trends:

- rapid expansion in the number of people in ICFs-MR from 1977-1982 (33%) followed by very little growth from 1982-1987 (2.6%), and actual decreases in ICF-MR facility residents in a majority of states;
- extensive certification of state institution capacity for ICF-MR participation (93% of residents were in certified units in June 1987);
- expanded ICF-MR certification of small, primarily private, residential settings (more than doubling residents between 1982 and 1987), but with most (80%) small facility care remaining non-ICF-MR certified;
- substantial, but decreasing concentration of ICF-MR beneficiaries and expenditures in large public and private residential facilities (84% of residents and 86% of expenditures in 1987).

These general trends in the ICF-MR program are reflected in the utilization patterns of a majority of states. Still there are very significant differences among the various states in their specific use of the program. This part of the report reviews both national and state-by-state utilization of the ICF-MR program to provide residential services to persons with mental retardation and related conditions. It includes an examination of factors affecting state decisions about participating in the program to finance parts of their residential service systems.

Background

In 1971 Congress joined under Title XIX, Medical Assistance, of the Social Security Act (SSA), the Intermediate Care Facility (ICF) program, which had been established in 1967 under Title XI of SSA,

and the Skilled Nursing Facility (SNF) program. The latter had been created in 1965 under Title XIX of the original legislation establishing the Medicaid program. Both programs were intended to provide nursing home care to needy individuals. To the legislation combining these programs, Congress also added authorization for a new optional program under Title XIX, the ICF-MR program, which, would provide federal financial participation (FFP) for the "care for the mentally retarded in public institutions, which have the primary purpose of providing health or rehabilitation services and which are classified as intermediate care facilities" (House Report 12934-3).

Congress responded to a number of problems then evident in authorizing this program, including: 1) helping states cover the steadily increasing costs of institutional care, growing at annual real dollar rate of 12% between 1965 and 1970 (Lakin, 1979); 2) creating incentives for states to maintain minimally adequate residential and habilitative programs in public institutions (Bellman, 1971); and 3) counteracting the rapidly growing practice of placing persons with mental retardation in private nursing homes or of certifying public mental retardation institutions as medical institutions (Skilled Nursing Facilities) in order to obtain FFP in the care of persons with mental retardation (Boggs, Lakin, & Clauser, 1985; GAO, 1970). Section 1905 of the amended Social Security Act specified that, in addition to meeting the standards of Intermediate Care Facilities in general, an ICF-MR would: 1) provide health and rehabilitation services to persons with mental retardation and related conditions; 2) provide a program of "active treatment"; and 3) provide assurances that federal funding would not supplant previously allocated state funding. States responded quickly to this new Medicaid option: by June 30, 1977, 43 states were participating in the program, with 574 ICF-MR certified facilities and 107,000 residents in certified units.

Most states were compelled to invest substantial funds to improve their institutional programs in order to initiate and/or maintain ICF-MR participation. From 1978-1980 about 750 million dollars in state funds were spent on capital projects alone, primarily in response to ICF-MR requirements (Gettings & Mitchell, 1980). This spending, and the long-term commitments to large public institutions it implied at a time of increasing support for community-based residential services, caused critics to charge that

the ICF-MR program 1) had created direct incentives for states to keep people with mental retardation in state institutions in order to obtain federal contributions of 50% to 80% of the costs of their care; 2) had diverted funds that could otherwise have been spent to develop more integrated, community-based programs into extremely costly institution renovations; and 3) had promoted numerous inefficiencies (and often enhanced dependency) by promoting a single uniform model of care into which people were being placed regardless of the nature and degree of their disabilities or their ability to benefit from less restrictive living arrangements (Taylor et al., 1981).

Regulations governing ICF-MR certification, first published in January 1974, were clearly oriented toward large congregate care facilities. However, recognizing the inefficiencies and/or inappropriateness of certain of these standards for smaller, community-based facilities, exceptions were permitted to a number of otherwise applicable standards in the case of facilities with 4 to 15 residents. (Intermediate care facilities, ICFs or ICFs-MR, must meet the Title XIX standard of having at least 4 "beds.") Despite the regulatory provisions that recognized and to some extent facilitated the development of small ICFs-MR, the numbers of such facilities actually developed varied enormously among states. While states in some federal regions (e.g., Region V) had developed hundreds of small ICFs-MR by 1980, other regions (e.g., II and X) had none. The variations among states and regions reflected what some states and national organizations considered to be a failure of the federal government to delineate clear and consistent policy guidelines for certifying small facilities. In response, in 1981, HCFA issued "Interpretive Guidelines for the Application of the 1974 Standards for Institutions for Intermediate Care Facilities Serving 15 or Fewer People." These guidelines did not change the existing standards for the ICF-MR program, but they did demonstrate how the standards for ICF-MR certification could be applied to programs delivering the ICF-MR level of care in facilities with from 4 to 15 residents. The guidelines were viewed as important in demonstrating the degree of flexibility available in providing the ICF-MR level of care in facilities of all sizes. It was anticipated by many that with these clarifications made, the ICF-MR level of care would be more readily available to persons in all sizes of residential facility and that ICF-MR beneficiaries would more often be able to reside in community settings while still being

afforded the health, safety, physical plant, and active treatment protections required in the program's regulations.

In October 1988, new ICF-MR regulations became effective. These represented substantially revised rules for the program participation. The new regulations are generally seen as more congruent than the earlier ICF-MR standards with many of the values and goals expressed by states and noted in Part I of the report. However, any perception of improvement in the standards is not being accompanied by increased ICF-MR program development. Despite the new standards, states are actually projecting decreased ICF-MR participation for the near future. At the time of our state surveys and case study interviews, states had not had experience with which to evaluate the practical implications of the amended standards.

Changing Patterns of ICF-MR Utilization

ICF-MR utilization has changed substantially in the past decade. This section of the report examines the status and changing patterns of national and state-by-state ICF-MR utilization at three points in time: June 30, 1977; June 30, 1982; and June 30, 1987.

General Participation

The ICF-MR program grew rapidly in the decade following enactment in 1971. By June 30, 1977 a total of 43 states were using the Medicaid ICF-MR option. On June 30, 1982 and on June 30, 1987, all states except Arizona and Wyoming were participating. (As of December 31, 1988 both Arizona and Wyoming were participating.) Six years after it began the ICF-MR program was serving 106,917 people (June 30, 1977). The number of residents in ICFs-MR increased another 32% from 1977 to June 30, 1982, when it had a total of 140,682 beneficiaries. However, from June 30, 1982 to June 30, 1987, the number of ICF-MR residents increased by only 3,668, or about 2.6%; and in a majority of states (26) the number of ICF-MR beneficiaries actually decreased. While a significantly greater proportion of the ICF-MR beneficiaries in 1987 were living in "small" facilities (i.e., 15 or fewer residents) than in previous years, the ICF-MR program remained overwhelmingly committed to institutional care.

In 1987, 83.7% of all ICF-MR residents were in large facilities (i.e., 16 or more residents) as compared with 93.1% in 1982 and 98.4% in 1977. In 1987 85.6% of federal reimbursements for ICF-MR care (or $2.6 billion) went to large facilities (Hemp, 1989).

State-Operated ICF-MR Certified Facilities

Despite growth in privately operated ICFs-MR in recent years, in Fiscal Year 1987 the ICF-MR program remained essentially a state institution program; 63.2% of ICF-MR residents lived in, and 74.5% of federal reimbursements went to, state facilities (Hemp, 1989); 96.9% of residents in state-operated ICFs-MR lived in large facilities. Figure 8 shows the distribution of ICF-MR residents in 1977, 1982, 1986, and 1987 among four basic categories of ICF-MR facility: 1) large state-operated facilities, 2) small state-operated facilities, 3) large nonstate facilities, and 4) small nonstate facilities. As noted in earlier parts of this report, large is defined as 16 and more residents, small as 15 and fewer. Nonstate facilities are overwhelmingly private, but include a few local government facilities. Table 4 shows the June 30, 1987 statistics on a state-by-state basis.

Large state-operated facilities. There was an overall decrease of about 18,932 residents of large state ICFs-MR nationwide between June 30, 1982 and June 30, 1987. This reflects the overall decrease in state institution populations over the period, even though the total proportion of state institution residents living in ICF-MR certified units increased from 87.5% to 93%. On June 30, 1982 there were 122,570 persons in state-operated institutions, 107,356 of whom were in ICF-MR certified units. On June 30, 1987 there were 95,052 persons in large state-operated facilities, 88,424 of whom were in ICF-MR certified units. This trend toward lower numbers of persons in large state institutions coupled with greater proportions of large state institution residents in ICF-MR units was evident in all but 6 states where the number of people in state-operated ICF-MR certified units increased.

There has been a notable change from an average increase of about 3,000 large state ICF-MR residents per year between 1977 and 1982 to an average decrease of about 4,000 per year between 1982 and 1987. Between June 30, 1977 and June 30, 1982 states were in the process of attaining certification for virtually all of the residential units of their institutions. By 1982 the vast majority of

institution units were already ICF-MR certified and the general depopulation of public institutions began causing substantial decreases in the number of residents in large state ICFs-MR.

The decreasing populations in state institutions continue to reduce the extent to which the ICF-MR program remains predominantly a state institution-centered program. Despite these reductions, it remains concentrated in large state institutions. In June 1987, 61.3% of all ICF-MR residents lived in large state facilities, down from 76.3% in 1982 and 87.1% in 1977; however, 72.1% of federal ICF-MR reimbursements still went to state institutions in 1987 because of their relatively higher costs. The average annual Medicaid expenditure for ICF-MR services in state institutions per ICF-MR beneficiary was about $44,400.

Small state-operated facilities. On June 30, 1987 there were 348 small (4-15 residents) state-operated, ICF-MR certified group homes operating in the United States. This represented 55.1% of all 632 small state-operated residential facilities nationwide. Only 2% (2,874) of all ICF-MR residents lived in these facilities. Although the rate of growth in the number of small state-operated ICF-MR facilities has been rapid, only 12 states were operating small ICFs-MR as of June 30, 1987, with 210 of the 348 (64.5%) located in New York and 54 (15%) located in Texas.

Nonstate ICF-MR Certified Facilities

Since 1977 there has been a strong trend toward greater "privatization" of ICF-MR care. In 1977 the 13,312 nonstate facility residents made up only 12.5% of all ICF-MR residents. By 1982, 31,974 nonstate ICF-MR residents made up 22.7% of all ICF-MR residents; and by 1987, 53,052 nonstate ICF-MR residents constituted 36.8% of all ICF-MR residents. Growth in the number of nonstate ICF-MR residents since 1977 has been evident in both large and small nonstate facilities.

Large nonstate facilities. The number of residents in large nonstate ICFs-MR increased by 20,440 (from 11,958 to 32,398 persons) between 1977 and 1987. This was more than the increase in residents of small ICFs-MR. Much of this growth took place between 1977 and 1982 (an increase of 11,654). During this period many states actively pursued the certification of existing nonstate institutions, which accounted for more of the growth than the development of new facilities. Growth slowed during

Figure 8
Residents of ICF-MR Certified Facilities by Size and Operator

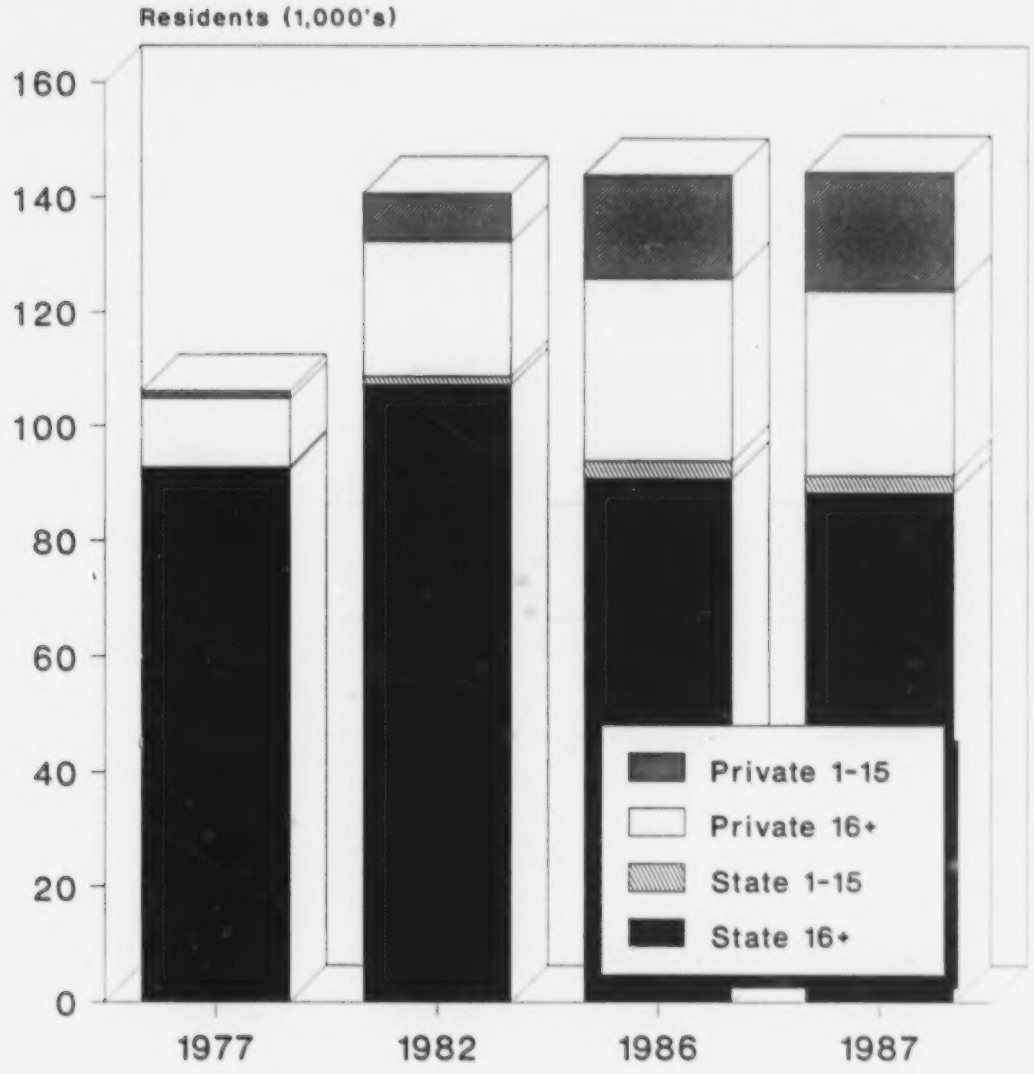


Table 4

ICF-MR Certified Facilities and Populations on June 30, 1987

State	ICF-MR Certified Facilities									Residents of ICF-MR Certified Facilities								
	Nonstate			State			By Size			Nonstate			State			By Size		
	15-	16+	Total	15-	16+	Total	15-	16+	Total	15-	16+	Total	15-	16+	Total	15-	16+	Total
ALABAMA	3	0	3	0	5	5	3	5	8	31	0	31	0	1,308	1,308	31	1,308	1,339
ALASKA	4	0	4	0	1	1	4	1	5	34	0	34	0	59	59	34	59	93
ARIZONA	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
ARKANSAS	0	3	3	0	6	6	0	9	9	0	124	124	0	1,337	1,337	0	1,461	1,461
CALIFORNIA	241	51	292	0	7	7	241	58	299	1,510	3,115	4,625	0	6,832	6,832	1,510	9,947	11,457
COLORADO	0	6	6	35	3	38	35	9	44	0	346	346	280	621	901	280	967	1,247
CONNECTICUT	25	1	26	35	10	45	60	11	71	138	17	155	255	953	1,208	393	970	1,363
DELAWARE	8	0	8	0	1	1	8	1	9	61	0	61	0	383	383	61	383	444
D.C.	61	0	61	0	1	1	61	1	62	375	0	375	0	258	258	375	258	633
FLORIDA	0	49	49	0	4	4	0	53	53	0	1,875	1,875	0	1,277	1,277	0	3,152	3,152
GEORGIA	0	1	1	0	8	8	0	9	9	0	110	110	0	1,839	1,839	0	1,949	1,949
HAWAII	7	0	7	1	1	2	8	1	9	29	0	29	8	260	268	37	260	297
IDAHO	13	2	15	0	1	1	13	3	16	124	58	182	0	263	263	124	321	445
ILLINOIS	72	46	118	0	12	12	72	58	130	738	4,191	4,929	0	4,471	4,471	738	8,662	9,400
INDIANA	300	5	305	0	7	7	300	12	312	1,984	593	2,577	0	1,491	1,491	1,984	2,084	4,068
IOWA	7	19	26	0	2	2	7	21	28	52	625	677	0	1,057	1,057	52	1,682	1,734
KANSAS	13	10	23	0	4	4	13	14	27	187	676	863	0	1,298	1,298	187	1,974	2,161
KENTUCKY	0	6	6	0	3	3	0	9	9	0	513e	513	0	686	686	0	1,199	1,199
LOUISIANA	145	18	163	6	9	15	151	27	178	805	1,547	2,352	33	2,889	2,922	838	4,436	5,274
MAINE	31	6	37	2	2	4	33	8	41	233	138	371	26	291	317	259	429	688
MARYLAND	0	0	0	1	7	8	1	7	8	0	0	0	12	1,452	1,464	12	1,452	1,464
MASSACHUSETTS	39	0	39	3	7	10	42	7	49	307	0	307	24	3,367	3,391	331	3,367	3,698
MICHIGAN	292	0	292	0	8	8	292	8	300	1,767	0	1,767	0	1,658	1,658	1,767	1,658	3,425
MINNESOTA	294e	53	347	7	7	14	301	60	361	2,819	2,049	4,868	28	1,653	1,681	2,847	3,702	6,549
MISSISSIPPI	0	5	5	0	5	5	0	10	10	0	605e	605	0	998	998	0	1,603	1,603
MISSOURI	14	3	17	2	10	12	16	13	29	121	137	258	16	1,874	1,890	137	2,011	2,148
MONTANA	1	0	1	0	2	2	1	2	3	10	0	10	0	254	254	10	254	264
NEBRASKA	0	3	3	0	1	1	0	4	4	0	344	344	0	472	472	0	816	816
NEVADA	1	0	1	0	2	2	1	2	3	15	0	15	0	175	175	15	175	190
NEW HAMPSHIRE	6	1	7	0	2	2	6	3	9	54	21	75	0	190	190	54	211	265
NEW JERSEY	0	2	2	0	9	9	0	11	11	0	72	72	0	3,757	3,757	0	3,829	3,829
NEW MEXICO	16	0	16	0	2	2	16	2	18	133	0	133	0	500	500	133	500	633
NEW YORK	486	31	517	210	34	244	696	65	761	4,243	1,172	5,415	1,853	10,022	11,875	6,096	11,194	17,290
NORTH CAROLINA	45	4	49	0	6	6	45	10	55	259	402	661	0	2,566	2,566	259	2,968	3,227
NORTH DAKOTA	61	0	61	0	2	2	61	2	63	496	0	496	0	398	398	496	398	892
OHIO	119	86	205	0	14	14	119	100	219	1,033	3,758	4,791	0	2,900	2,900	1,033	6,658	7,691
OKLAHOMA	0	22	22	0	3	3	0	25	25	0	1,794	1,794	0	1,145	1,145	0	2,939	2,939
OREGON	2	4	6	0	2	2	2	6	8	22	219	241	0	1,145	1,145	22	1,364	1,386
PENNSYLVANIA	86	21	107	0	17	17	86	38	124	441	1,969	2,410	0	5,127	5,127	441	7,096	7,537
RHODE ISLAND	93	2	95	25	2	27	118	4	122	507	32	539	175	280	455	682	312	994
SOUTH CAROLINA	55	3	58	2	5	7	57	8	65	507	76	583	22	2,534	2,556	529	2,610	3,139
SOUTH DAKOTA	16	0	16	0	2	2	16	2	18	195	0	195	0	485	485	195	485	680
TENNESSEE	1	4	5	0	4	4	1	8	9	12	188	200	0	2,089	2,089	12	2,277	2,289
TEXAS	127	31	158	54	16	70	181	47	228	860	2,685	3,545	422	7,936	8,358	1,282	10,621	11,903
UTAH	2	9	11	0	1	1	2	10	12	30	581	611	0	540	540	30	1,121	1,151
VERMONT	9	0	9	0	1	1	9	1	10	54	0	54	0	196	196	54	196	250
VIRGINIA	9	3	12	0	5	5	9	8	17	91	108	199	0	2,970	2,970	91	3,078	3,169
WASHINGTON	23	12	35	0	6	6	23	18	41	145	598	743	0	1,810	1,810	145	2,408	2,553
WEST VIRGINIA	20	0	20	0	2	2	20	2	22	194	0	194	0	210e	210e	194	210	404
WISCONSIN	3	19	22	0	3	3	3	22	25	40	1,660	1,700	0	1,868	1,868	40	3,528	3,568
WYOMING	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
U.S. Total	2,750	541	3,291	348	274	622	3,098	815	3913	20,654	32,398	53,052	2,874	88,424	91,298	23,528	120,822	144,350

the period between 1982 and 1987, with an overall increase of 8,786 residents in large nonstate ICF-MR. States reported an increase of only 453 residents during the period from June 30, 1986 to June 30, 1987. Three states accounted for most (54.6%) of the total increase in large nonstate ICF-MR residents between 1982 and 1987: Ohio (3,758), Florida (1,875), and Oklahoma (1,794). In the case of Oklahoma this increase represented neither newly established facilities, nor even new Medicaid funding, but came primarily from the recertification of mental retardation facilities that were previously operated under ICF-general (nursing homes) certification.

The average number of residents per large nonstate facility declined throughout the period between 1977 and 1987. The national average decreased from 76 to 66 residents between 1977 and 1982, and from 66 to 60 residents between 1982 and 1987. In Fiscal Year 1987, large nonstate ICFs-MR had an average daily cost per resident ($22,800) that was far below the average of $38,800 for all ICF-MR residents. A significant factor in these differences is that large nonstate ICFs-MR tend to serve a population with less severe impairments than those served by large public ICFs-MR. (32% of large nonstate ICF-MR residents were profoundly retarded in 1987 compared with 63% of residents of large state ICFs-MR in 1987).

Small nonstate facilities. The 2,750 small nonstate ICF-MR certified facilities constituted over two-thirds (70.3%) of the total number of certified facilities as of June 30, 1987. But only 14.3% of the total ICF-MR residents lived in small nonstate facilities. These numbers compare with 26% of facilities and 1.3% of residents in 1977, at a time when only 10 states had certified small nonstate ICFs-MR, and 56% of facilities and 6% of residents in 1982, when 35 states had small nonstate ICFs-MR. On June 30, 1987, 39 states had one or more small, nonstate ICF-MR certified facilities, with the number ranging from 486 (New York) to 1 (Montana, Nevada, and Tennessee).

In 1977 Minnesota, the earliest adopter of the small ICF-MR option, had 77% of all small nonstate ICF-MR group homes nationwide (113) and 78% of all residents. By 1982, small nonstate ICFs-MR were no longer predominantly a Minnesota program, but there remained a strong tendency toward concentration in a few states. On June 30, 1982, Minnesota and New York together had a majority

(51.5%) of all small nonstate ICF-MR residents nationally (28.8% and 22.7% respectively). By June 30, 1987, although they continued to be the most intense users of small nonstate ICFs-MR, their combined proportion of the national total had dropped to 35.7% of the residents and 28.4% of the total number of small nonstate ICF-MR facilities. The average annual cost of care for small nonstate ICF-MR residents in Fiscal Year 1987 was about $31,600 or 71% of the average annual cost for all ICF-MR residents (Hemp, 1989).

Distribution of ICF-MR Residents

The size of a residential facility has an obvious effect on the likelihood that its residents will have a culturally typical living environment: most people do not live in large institutions. Studies of long-term gains in adaptive behavior of persons released from large state institutions to small community-based facilities consistently indicate better developmental outcomes to be associated with the latter. Although facilities with as many as 15 residents are not particularly small by contemporary standards, size breaks of 15 or fewer versus 16 or more residents are typically used for classifying facilities by size because of dichotomous distinctions in the Life Safety Code and in the ICF-MR standards, and because of other formal determinations of institutional/noninstitutional living (e.g., provisions of the federal food stamp program, S.S.I. eligibility), as well as traditional use within the residential services field. This size break is therefore used in the discussion of the distribution of ICF-MR residents throughout this report.

Table 5 reports by state and by facility size the total number of persons with mental retardation in all residential facilities for persons with mental retardation (ICF-MR and non-ICF-MR), the number of persons in ICFs-MR, and the percentages of all residents residing in ICFs-MR, with no distinction made between state-operated and nonstate-operated facilities. It shows a total of 118,570 persons in small residential facilities nationwide on June 30, 1987, of whom 23,528 were living in small ICFs-MR. Nationally, 46.4% of all facility residents were in small facilities. In contrast only 16.3% percent of ICF-MR residents were living in small ICFs-MR. A total of 26 states reported more than half their total residents in small facilities on June 30, 1987 but only 4 states reported more than half their ICF-MR

Table 5

Number and Percentage of Residents in ICF-MR Certified and Noncertified

Facilities by State and Facility Size on June 30, 1987

State	ICF-MR Residents			All Residents				Percentage in ICF-MR		
	15-	16+	Total	15-	16+	Total	% in 15-	15-	16+	Total
ALABAMA	31	1,308	1,339	529	1,447	1,976	26.77%	5.86%	90.39%	67.76%
ALASKA	34	59	93	247	83	330	74.85%	13.77%	71.08%	28.18%
ARIZONA	0	0	0	1,796	423	2,219	80.94%	.00%	.00%	.00%
ARKANSAS	0	1,461	1,461	455	1,471	1,926	23.62%	.00%	99.32%	75.86%
CALIFORNIA	1,510	9,947	11,457	17,849	11,054	28,903	61.75%	8.46%	89.99%	39.64%
COLORADO	0	1,247	1,247	1,699	1,247	2,946	57.67%	.00%	100.00%	42.33%
CONNECTICUT	393	970	1,363	2,436	2,384	4,820	50.54%	16.13%	40.69%	28.28%
DELAWARE	61	383	444	297	383	680	43.68%	20.54%	100.00%	65.29%
D.C.	375	258	633	731	258	989	73.91%	51.30%	100.00%	64.00%
FLORIDA	0	3,152	3,152	3,247	4,952	8,199	39.60%	.00%	63.65%	38.44%
GEORGIA	0	1,949	1,949	1,242	2,227	3,469	35.80%	.00%	87.52%	56.18%
HAWAII	37	260	297	581	260	841	69.08%	6.37%	100.00%	35.32%
IDAHO	124	321	445	973	321	1,294	75.19%	12.74%	100.00%	34.39%
ILLINOIS	738	8,662	9,400	3,021	10,425	13,446	22.47%	24.43%	83.09%	69.91%
INDIANA	1,984	2,084	4,068	4,523	5,863	10,386	46.84%	78.64%	72.79%	75.53%
IOWA	52	1,682	1,734	1,168	2,183	3,351	34.86%	4.45%	77.05%	51.75%
KANSAS	187	1,974	2,161	1,781	1,974	3,755	47.43%	10.50%	100.00%	57.55%
KENTUCKY	0	1,199	1,199	430	1,199	1,629	26.40%	.00%	100.00%	73.60%
LOUISIANA	838	4,436	5,274	1,205	4,436	5,641	21.36%	69.54%	100.00%	93.49%
MAINE	259	429	688	1,305	568	1,873	69.67%	19.85%	75.53%	36.73%
MARYLAND	12	1,452	1,464	2,624	1,532	4,156	63.14%	.46%	94.78%	35.23%
MASSACHUSETTS	331	3,367	3,698	3,762	3,430	7,192	52.31%	8.80%	98.16%	51.42%
MICHIGAN	1,767	1,658	3,425	5,506	2,333	7,839	70.24%	32.09%	71.07%	43.69%
MINNESOTA	2,847	3,702	6,549	5,017	3,772	8,789	57.08%	56.75%	98.14%	74.51%
MISSISSIPPI	0	1,603	1,603	317	5,127	5,444	12.97%	.00%	75.36%	69.59%
MISSOURI	137	2,011	2,148	2,280	3,671	5,951	38.31%	6.01%	54.78%	36.09%
MONTANA	10	254	264	913	254	1,167	78.23%	1.10%	100.00%	22.62%
NEBRASKA	0	816	816	1,349	816	2,165	62.31%	.00%	100.00%	37.69%
NEVADA	15	175	190	258	175	433	59.58%	5.81%	100.00%	43.88%
NEW HAMPSHIRE	54	211	265	913	211	1,124	81.23%	5.91%	100.00%	23.58%
NEW JERSEY	0	3,829	3,829	3,018	5,376	8,394	35.95%	.00%	71.22%	45.62%
NEW MEXICO	133	500	633	902	500	1,402	64.34%	14.75%	100.00%	45.15%
NEW YORK	6,096	11,194	17,290	16,043	11,274	27,317	58.73%	38.00%	99.29%	63.29%
NORTH CAROLINA	259	2,968	3,227	1,229	3,261	4,490	27.37%	21.07%	91.02%	71.87%
NORTH DAKOTA	494	398	892	971	441	1,412	68.77%	50.88%	90.25%	63.17%
OHIO	1,033	6,658	7,691	4,438	6,860	11,298	39.28%	23.28%	97.06%	68.07%
OKLAHOMA	0	2,939	2,939	817	3,014	3,831	21.33%	.00%	97.51%	76.72%
OREGON	22	1,364	1,386	1,666	1,476	3,142	53.02%	1.32%	92.41%	44.11%
PENNSYLVANIA	441	7,096	7,537	6,654	8,151	14,805	44.94%	6.63%	87.06%	50.91%
RHODE ISLAND	682	312	994	861	312	1,173	73.40%	79.21%	100.00%	84.74%
SOUTH CAROLINA	529	2,610	3,139	1,251	2,610	3,861	32.40%	42.29%	100.00%	81.30%
SOUTH DAKOTA	195	485	680	1,076	485	1,561	68.93%	18.12%	100.00%	43.56%
TENNESSEE	13	2,277	2,289	1,486	2,308	3,794	39.17%	.81%	98.66%	60.33%
TEXAS	1,283	10,621	11,903	2,014	10,894	14,908	15.60%	63.65%	97.49%	95.51%
UTAH	30	1,121	1,151	560	1,135	1,695	33.04%	5.36%	98.77%	67.91%
VERMONT	54	196	250	381	196	577	66.03%	14.17%	100.00%	43.33%
VIRGINIA	91	3,078	3,169	754	3,078	3,832	19.68%	12.07%	100.00%	82.70%
WASHINGTON	145	2,408	2,553	2,726	2,823	5,549	49.13%	5.32%	85.30%	46.01%
WEST VIRGINIA	194	210	404	868	553	1,421	62.40%	22.35%	40.15%	29.04%
WISCONSIN	40	3,528	3,568	4,190	3,528	7,718	54.29%	.95%	100.00%	46.23%
WYOMING	0	0	0	211	409	620	34.03%	.00%	.00%	.00%
U.S. Total	23,528	120,822	144,350	118,570	137,133	255,703	46.37%	19.84%	88.11%	56.45%

residents in small facilities. States with at least 40% of their total ICF-MR population in small facilities included the District of Columbia (59.2%), Indiana (48.8%), Michigan (51.6%), Minnesota (43.5%), North Dakota (55.4%), Rhode Island (68.6%), and West Virginia (48.0%). In contrast, eleven states with ICF-MR programs had no small ICF-MR certified facilities.

Of all persons in mental retardation facilities, as of June 30, 1987, 56.5% were in facilities with ICF-MR certification. Among large public and private residential facilities in 1987, 88.1% of residents were in ICFs-MR. While statistics continue to show the ICF-MR program to be primarily concentrated in institutions, they reveal some shift over time to greater total and proportional use of Title XIX funding for small facilities. This shift is reflected in Figure 9. For example, in 1977, only 4.3% (1,725) of the total 40,400 persons in small residential settings were in settings certified for ICF-MR participation. In 1982, 15.2% (9,714) of 63,700 persons in small residential facilities were in facilities with ICF-MR certification. By 1987, the percentage of all persons in small residential facilities who were living in ICF-MR certified facilities had increased to 19.8% (23,528) of 118,570 total residents.

A number of states entered and/or substantially increased their use of small ICFs-MR between 1982 and 1987. Notable among these were California which increased from 0 to 1,510 small ICF-MR residents; Indiana, which increased from 337 to 1,984; and New York, which increased from 2,289 to 6,096. In 16 states there were increases of 190 or more persons in small ICFs-MR between June 1982 and June 1987. Nevertheless, the predominance of just a few states in the relative utilization of the small ICF-MR option was still notable in 1987. On June 30, 1987 three states had at least two-thirds of their small facility residents in facilities with ICF-MR certification (Indiana, 78.6%; Louisiana, 69.5%; Rhode Island, 79.2%). Indeed, excluding these three states only 16.8% of residents in small facilities in the remaining 48 states were in ICFs-MR. Sixteen states had less than 10% of their small facility residential populations in ICF-MR; 11 states had no small ICF-MR certified facilities at all.

To facilitate comparison of ICF-MR utilization among states of different sizes, it is often useful to index such statistics by the general state population. Table 6 provides an index of states' ICF-MR residents per 100,000 of states' total population as of June 30, 1987. It permits interstate comparisons

of the utilization of ICF-MR services in small, large, and total residential facilities. Because of the direct link of Medicaid Home and Community-based ("waiver") Services to ICF-MR utilization, as discussed in Part IV of this report, utilization of waiver services is also shown in Table 6. Table 6 shows that nationally there has been an overall reduction in ICF-MR utilization; an increase in small ICF-MR use; and a decrease in the utilization rate in large ICF-MR. The average number of ICF-MR residents per 100,000 of the U.S. population on June 30, 1987 was 59.3 (down from 60.8 in 1982). This included 9.7 persons per 100,000 in small ICFs-MR (up from 4.2 in 1982) and 49.7 persons per 100,000 in large ICFs-MR (down from 56.6).

Remarkable variation in ICF-MR utilization is evident among the states. Minnesota had by far the highest utilization rate nationally, with 154.3 ICF-MR residents per 100,000 of the state's population. North Dakota (132.3/100,000) had greater than twice the national average. A total of 9 states had ICF-MR utilization rates that were more than 150% above the national average. In contrast 7 states had less than 50% of the national rate. Excluding Arizona and Wyoming, which did not participate in the program as of June 30, 1987, the lowest utilization rate was 17.1/100,000 (Alaska), followed by Nevada (19.1/100,000) and West Virginia (21.2/100,000). The range for utilization of large ICF-MR was from 98.5/100,000 (Louisiana) to 10.8/100,000 (Alaska), again excluding Arizona and Wyoming. States besides Louisiana with the highest utilization rates for large ICF-MR include Minnesota (87.2/100,000), Oklahoma (89.2/100,000), and Kansas (80.0/100,000). In contrast eight states reported rates below 25/100,000 for large ICF-MR utilization. But by far the greatest interstate variability was evident in the small ICF-MR utilization rates. These rates ranged from more than 50 per 100,000 in the District of Columbia (60.4), Minnesota (67.1), North Dakota (73.3), and Rhode Island (69.5) to less than 3.0 per 100,000 in 22 states.

If one includes both ICF-MR and Medicaid waiver utilization, the total national number of Medicaid beneficiaries for each 100,000 of the U.S. population on June 30, 1987 was 68.7. Including Medicaid waiver service recipients and small ICF-MR residents, the proportion of U.S. citizens receiving community-based services under Medicaid was 19 per 100,000, as compared with 49.7 for ICF-MR funded institutional services.

Figure 9
Number of Residents in Large and Small Facilities by ICF-MR Certification

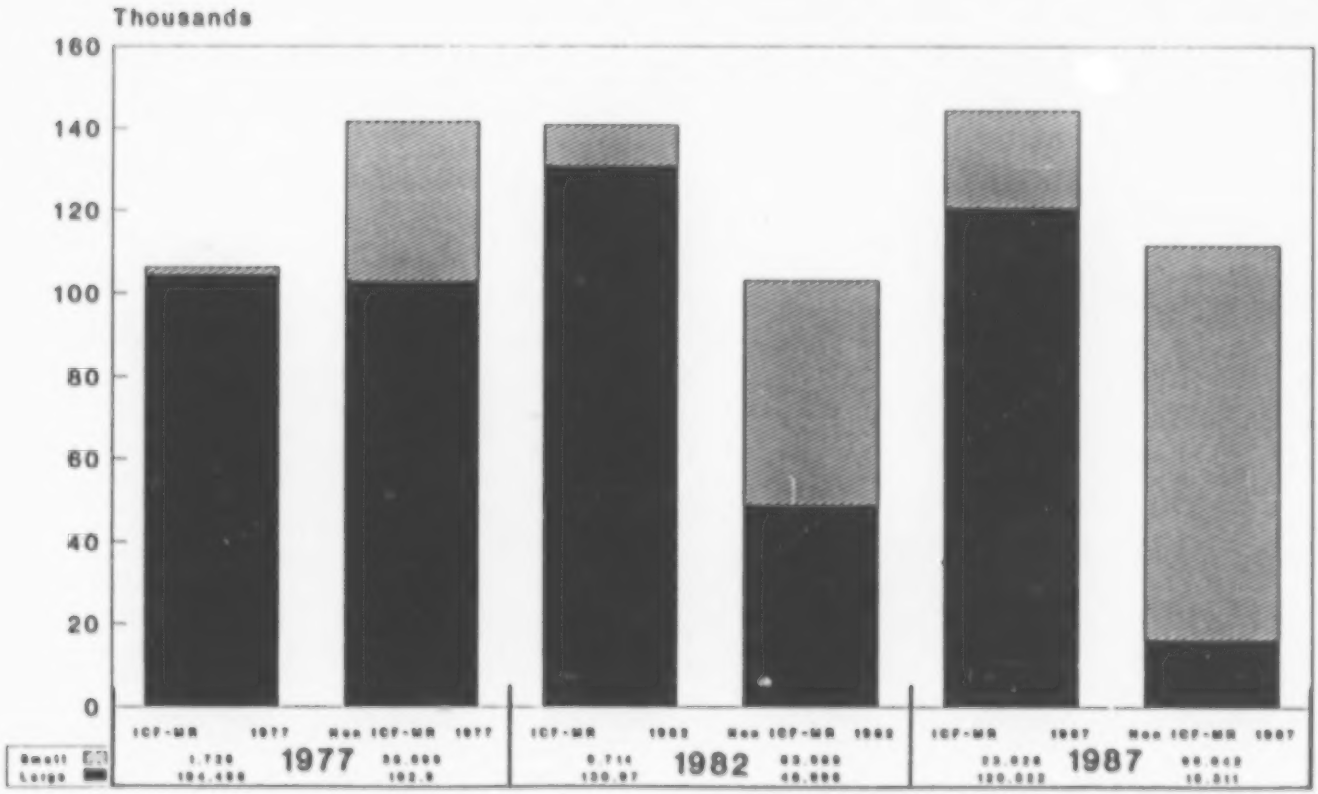


Table 6

Utilization Rates per 100,000 of State Population:

Large and Small ICF-MR and Total Residential Facilities

State	7/1/87 State Pop.	ICF-MR Residents 15-	16+	Total	ICF-MR 15- and Waiver	Total ICF-MR and Waiver	ICF-MR and Non-ICF-MR 15-	16+	Total
ALABAMA	40.86	.8	32.0	32.8	39.2	71.2	12.9	35.4	48.4
ALASKA	5.44	6.3	10.8	17.1	6.3	17.1	45.6	15.3	60.7
ARIZONA	3.32	.0	.0	.0	.0	.0	52.3	12.3	64.7
ARKANSAS	23.86	.0	61.2	61.2	.0	61.2	19.1	61.7	80.7
CALIFORNIA	27.31	5.5	36.1	41.6	16.5	52.6	64.8	40.2	105.0
COLORADO	33.08	.0	32.7	32.7	46.0	78.7	55.8	33.2	89.1
CONNECTICUT	32.12	12.2	30.2	42.4	16.2	42.4	73.8	76.2	150.1
DELAWARE	6.41	9.5	59.8	69.3	22.2	81.9	46.2	59.8	106.1
D.C.	6.21	60.4	41.5	101.9	60.4	101.9	117.7	41.5	159.3
FLORIDA	119.62	.0	26.4	26.4	22.0	48.3	27.1	41.4	68.5
GEORGIA	62.44	.0	31.2	31.2	.0	31.2	19.9	35.7	55.6
HAWAII	10.81	3.6	24.1	27.5	8.6	32.9	53.7	51.9	105.6
IDAHO	10.06	12.3	31.9	44.5	17.8	46.7	66.7	61.9	128.6
ILLINOIS	115.69	6.4	74.9	81.3	12.1	81.0	29.1	90.1	119.2
INDIANA	55.18	36.0	37.8	73.7	36.0	73.7	45.7	51.9	97.6
IOWA	28.26	1.8	59.5	61.4	2.0	61.5	41.3	77.2	118.6
KANSAS	25.69	7.6	80.0	87.5	13.0	93.0	72.1	80.0	152.1
KENTUCKY	37.33	.0	32.1	32.1	16.3	48.4	11.9	32.1	43.9
LOUISIANA	45.02	18.0	98.5	116.1	18.9	119.1	26.8	98.5	125.3
MAINE	11.86	21.9	36.5	58.1	52.7	91.9	100.5	58.0	158.5
MARYLAND	45.32	.3	55.0	55.3	12.4	57.4	57.0	58.8	115.8
MASSACHUSETTS	58.38	5.7	57.7	63.5	15.8	73.5	64.6	58.8	123.2
MICHIGAN	91.91	19.2	18.0	37.5	19.3	37.5	59.9	25.4	85.3
MINNESOTA	42.43	67.1	87.2	154.5	100.6	187.9	118.2	88.9	207.1
MISSISSIPPI	26.45	.0	60.9	60.9	.0	60.7	12.0	80.5	92.5
MISSOURI	51.00	2.2	39.4	41.5	2.2	42.1	44.0	72.5	116.5
MONTANA	8.14	1.5	51.5	53.4	29.0	58.2	112.2	31.5	143.6
NEBRASKA	15.95	.0	51.2	51.2	.0	52.4	84.6	51.2	135.8
NEVADA	9.93	1.5	17.6	19.1	14.5	32.5	20.0	23.6	43.6
NEW HAMPSHIRE	10.58	9.1	19.9	25.0	56.2	76.2	86.3	19.9	106.2
NEW JERSEY	79.87	.0	49.8	49.8	33.8	83.6	39.3	60.9	100.2
NEW MEXICO	15.18	8.8	32.9	41.7	33.8	56.2	59.6	32.9	92.5
NEW YORK	177.56	34.5	63.0	97.4	57.5	97.4	90.1	63.5	153.6
NORTH CAROLINA	64.52	14.0	46.5	60.5	9.1	55.4	19.1	50.8	69.9
NORTH DAKOTA	6.74	73.3	59.1	132.3	180.7	239.8	144.1	65.4	209.5
OHIO	107.67	9.6	61.8	71.4	10.5	72.4	41.2	63.7	104.9
OKLAHOMA	32.95	.0	89.2	89.2	2.1	91.3	24.8	91.3	116.2
OREGON	29.16	.8	50.2	51.0	31.4	81.7	61.3	54.3	115.7
PENNSYLVANIA	118.74	3.8	59.8	63.5	13.4	73.6	56.0	66.3	122.7
RHODE ISLAND	9.82	66.5	31.6	101.1	8.5	115.1	89.7	30.3	119.5
SOUTH CAROLINA	34.50	15.3	76.3	91.6	15.5	91.8	19.6	93.3	112.9
SOUTH DAKOTA	7.07	27.6	68.0	96.5	111.9	190.5	152.6	86.6	239.2
TENNESSEE	48.48	.0	41.0	41.0	6.6	47.6	30.5	46.3	76.8
TEXAS	169.37	7.9	62.7	70.5	8.0	70.7	11.9	64.3	76.2
UTAH	16.94	1.8	66.2	68.0	1.8	67.9	33.1	67.3	100.4
VERMONT	5.47	9.0	55.8	64.7	45.7	81.5	69.7	35.8	105.5
VIRGINIA	58.83	1.5	52.4	53.9	1.5	53.7	12.8	52.5	65.3
WASHINGTON	42.14	3.5	53.5	56.9	22.8	79.2	66.4	69.2	135.9
WEST VIRGINIA	19.02	10.5	11.0	21.5	16.7	38.8	42.0	37.5	79.5
WISCONSIN	47.91	.8	73.6	74.5	4.8	78.4	81.2	20.8	102.1
WYOMING	5.06	.0	.0	.0	.0	.0	41.7	80.8	122.5
U.S. Total	2,433.05	9.7	49.7	59.3	19.0	68.7	48.7	56.4	105.1

Characteristics of ICF-MR Residents

Resident Characteristics

Statistics on selected characteristics of persons with mental retardation and related conditions living in ICF-MR and noncertified residential facilities indicate that ICF-MR certified facilities serve a substantially different population than the population served in noncertified facilities. Table 7 presents information which shows that residents of ICFs-MR tend to be somewhat older, are more likely to have profound mental retardation, have fewer skills in activities of daily living (ADL), and have health conditions generally similar to residents of non-ICF-MR certified facilities. The data presented are from the 1987 National Medical Expenditure Survey. In Table 7, facilities are further distinguished as small (15 or fewer "set up beds") or large (16 or more "set up beds"). Totals for all facilities are also provided.

Resident ages. The age distribution of the resident population of ICFs-MR is not dramatically different than the population of noncertified facilities. Both types of facility are overwhelmingly populated by adults, with more than two-thirds of their residents in the 22-54 year age group. Only an estimated 13% of residents of both types of facility were 55 years or older. Differences were found, however, in the proportion of children and youth (0-21 years) in ICFs-MR and other types of residence. An estimated 13.7% of ICF-MR residents and 18.4% of non-ICF-MR residents were 21 years or younger. The major factor in the difference was the high representation of state institutions residents in the ICF-MR population. As was noted earlier in this report, states have dramatically reduced the number and proportion of children and youth in state institutions in the past several years.

Over the past decade there have been very significant decreases in the number of children and youth residing in ICF-MR facilities. As a proportion of total ICF-MR residents the decrease was substantially greater than the estimated decrease of 47% in the total number of children and youth in all mental retardation facilities between 1977 and 1987. In 1977, 35.6% of ICF-MR residents were ages birth to 21 years. In 1982, 22.6% of ICF-MR residents were 21 years old or younger. In 1987, that proportion had decreased to an estimated 13.7%. In other words even though the ICF-MR population

Table 7

Selected Characteristics of Residents with Mental Retardation and Related Conditions in ICF-MR and Non-ICF-MR Certified Residential Facilities by Size[1] in 1987[2]

	ICF-MR Certified			Not ICF-MR Certified			All Facilities		
	15- res. (21,077)	16+ res. (118,084)	Total (139,161)	15- res. (43,859)	16+ res. (35,613)	Total (79,472)	15- res. (64,936)	16+ res. (153,697)	Total (218,633)
Age									
0-14	2.0	4.4	4.0	3.2	6.1	5.6	4.2	4.8	4.6
15-21	8.6	9.8	9.7	10.4	15.6	12.8	9.9	11.2	10.8
22-39	54.0	53.3	53.4	51.0	45.5	48.5	52.0	51.5	51.6
40-54	23.8	18.7	19.5	20.8	19.6	20.3	21.8	18.9	19.8
55-64	8.0	7.5	7.6	7.2	9.0	8.0	7.5	7.8	7.7
65+	3.5	6.3	5.8	5.4	4.2	4.8	4.8	5.8	5.5
Disabilities									
Mental Retardation Indicated									
Borderline	3.5	2.4	2.6	6.0	8.5	7.1	5.2	3.7	4.1
Mild	26.3	9.4	12.0	34.9	26.5	25.6	25.4	13.2	16.8
Moderate	27.7	13.4	15.6	33.2	28.3	31.0	31.4	16.7	21.0
Severe	25.4	19.7	20.5	22.6	17.5	20.3	23.3	19.2	20.5
Profound	16.3	54.3	48.8	12.1	17.4	15.3	13.6	46.3	36.7
Total	99.4	99.4	99.5	98.8	98.2	98.5	99.1	99.1	99.1
Not MR/Related Conditions									
Epilepsy only	.2	.4	.4	.9	1.2	1.1	.7	.6	.6
Cerebral palsy only	.3	.2	.2	.2	.3	.2	.2	.2	.2
Autism only	0.0	0.0	0.0	.1	0.0	0.0	.1	0.0	0.0
Spina bifida only	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Multiple related conditions	0.0	0.0	0.0	0.0	.2	.1	0.0	0.0	0.0
Total	.5	.6	.6	1.2	1.7	1.4	1.0	.8	.8
Activities of Daily Living									
Dressing									
No difficulty w/o help	61.8	31.6	36.2	63.1	61.1	62.2	62.6	38.4	45.6
Uses special equipment/no other assistance	.2	0.0	0.0	.1	.2	.2	0.2	0.0	0.1
Received assistance or supervision	38.0	68.4	63.8	36.8	38.7	37.7	37.2	61.5	54.3
Using the toilet									
No difficulty w/o help	86.6	54.2	59.1	85.7	81.2	83.7	86.0	60.6	68.1
Uses special equipment/no other assistance	.2	.1	.1	.4	0.0	.2	0.4	0.1	0.2
Received assistance or supervision	12.2	31.1	28.2	11.2	13.4	12.1	11.5	27.0	22.4
Did not do at all	1.0	14.6	12.5	2.6	5.5	3.9	2.1	12.5	9.4
Walking across room									
No difficulty w/o help	92.8	66.4	70.5	90.3	87.7	89.2	91.2	71.4	77.3
Uses special equipment/no other assistance	1.1	1.5	1.4	.9	.8	.8	0.9	1.3	1.2
Received assistance or supervision	4.7	11.4	10.4	5.2	6.4	6.8	7.0	9.8	8.4
Did not do at all	1.3	20.7	17.7	3.6	7.1	5.2	2.9	17.5	13.2
Medical Conditions									
Circulatory conditions[3]	11.5	10.5	10.7	12.6	9.8	11.3	12.2	10.3	10.9
Arthritis or rheumatism	4.3	4.3	4.3	5.5	4.6	5.1	5.1	4.4	4.6
Diabetes	2.1	1.9	1.9	2.0	2.4	2.2	2.0	2.0	2.0
Cancer	1.9	1.2	1.3	0.6	1.4	1.0	1.6	1.3	1.2
Frequent constipation	11.7	29.1	26.4	11.5	10.6	11.1	11.5	26.8	20.9
Obesity	10.6	12.6	12.1	17.3	12.6	15.2	15.1	12.4	13.2

[1] Facility size groupings based on number of "set up beds" in facility (or its mental retardation unit). Some facilities may be larger than the size of their mental retardation unit. Columns marked 15- res indicate facilities or mental retardation units with 15 or fewer "set up beds;" 16+ res indicates 16 or more "set up beds."
[2] Data are from the National Medical Expenditure Survey.
[3] Includes present high blood pressure, hardening of the arteries or heart disease; or past stroke or heart attack.

as a whole increased by 37,433 total residents (or 26%) between 1977 and 1987, the number of children and youth *decreased* by 48% over the same period. Between 1982 and 1987, the total number of children and youth who were ICF-MR "beneficiaries" decreased by about 12,000 to an estimated 19,775.

Resident diagnosis. ICF-MR residents are *on the average* considerably more severely impaired than residents of noncertified facilities. While an estimated 49% of the ICF-MR population is reported to have profound mental retardation, the comparable estimates for noncertified facilities was only 14.5%. Similar differences were evident for residents reported to have borderline, mild, or moderate mental retardation. While an estimated 30% of the ICF-MR population was so classified, this was much less than the estimated 64% of the residents of noncertified facilities so classified.

The 1987 ICF-MR population appears generally comparable to the 1982 ICF-MR population. The estimated 49% of the 1987 residents with profound retardation is statistically equal to the 50% obtained in the 1982 census survey. On the other hand, in 1982, 25% of the ICF-MR population was reported to be borderline, mild, or moderately retarded. Despite considerable debate within professional circles in the past several years about the appropriateness of the ICF-MR level of care for most individuals in these diagnostic categories, by 1987 the proportion of ICF-MR residents so classified had increased to an estimated 30%. A significant factor in this shift was the increasing use of small ICFs-MR which tend to serve persons with borderline, mild, or moderate mental retardation (57.5%) and the use of the Medicaid Home and Community-based Services waiver to serve persons with severe and profound mental retardation who were (or otherwise would have been) living in ICFs-MR (see Part IV). Relatively few of the ICF-MR residents (an estimated .6%) were reported to have epilepsy, cerebral palsy, autism, or spina bifida without also being indicated as "mentally retarded."

Resident activities of daily living. As expected from the statistics showing a generally more cognitively impaired population in ICFs-MR, ICF-MR residents were reported to be considerably more dependent than non-ICF-MR residents (i.e., needed assistance of another person or the assistance of equipment). Substantial differences were found in selected activities of daily living (ADLs) which included dressing (36% and 62% for ICF-MR and non-ICF-MR residents, respectively), toileting (59% and

84%, respectively) and walking across the room (72% and 90%, respectively). The only facility populations contributing significantly to the differences noted were the large ICF-MR facilities, principally state institutions. Rather remarkable patterns of similarity were noted in the ADLs of the resident populations of small ICFs-MR and both small and large noncertified facilities.

Medical conditions. Of the selected medical conditions gathered in the baseline interview of the National Medical Expenditure Survey, only one showed variation among residents of different types of facilities. Residents of large ICFs-MR were substantially more likely to be reported to have frequent constipation than residents of other facility types (29% and 11%). Identification of constipation as a persistent problem in large government ICF-MR facilities is common. The generally accepted reasons for the high prevalence among this group are factors assumed to be associated with the severity and complications of disability, relating to lack of movement and upright mobility, relatively low fluid intake and diet. It is assumed that chronic constipation is exacerbated by neuromuscular disorders and abdominal muscle weaknesses in the institutionalized population (Browne & Walsh, 1989).

Obesity was reported to be somewhat more common among residents of small noncertified facilities (17% versus 12% for other facilities). Other conditions were reported to be similarly distributed among residents of the different types of facility. Diabetes was found to be slightly less frequent among residents of mental retardation facilities than the general population (2.0% and 2.5% respectively; NCHS, 1986). Other health conditions appear less frequent than among the general population, although clearly comparable statistics were not available for comparison.

Projections of ICF-MR Utilization

There was a total of 144,350 persons with mental retardation and related conditions in ICF-MR certified facilities as of June 30, 1987. In the state survey, state agency respondents were asked to project residential population changes in ICF-MR utilization between June 30, 1987 and June 30, 1990. These projected changes are shown in Table 8 for large state-operated, small state-operated, large nonstate and small nonstate ICFs-MR. Table 8 also summarizes the factors that states believe will be

most influential in the projected changes. These include increased use of community-based alternatives; increase of community-based alternatives via use of a Home and Community-based Services (HCBS) waiver; anticipation of federal Medicaid reform legislation, such as the Chafee Home and Community Quality Services Act; HCFA standards and program monitoring activities, including compliance with the new ICF-MR standards, stricter surveys, federal "look behind" activities, and utilization reviews; budget reductions and constraints; state legislation; institution/facility closures; waiting lists; and implementation of P.L. 100-203 (OBRA 1987). General agency planning and policies are not listed in Table 8 because they are nearly universally indicated as an important factor.

Large state ICFs-MR. Nearly all states (46) anticipate a stable or declining number of persons in large state-operated ICFs-MR. States anticipating the most significant decrease in large state-operated populations include Rhode Island (-75%), Hawaii (-55%) and New Hampshire (-50%). Eleven states projected no significant change in the number of persons in large state-operated ICFs-MR. Three states expect increases in the number of persons residing in large state-operated ICFs-MR, with West Virginia projecting a 21% increase, Missouri an 8% increase, and Nevada a 5% increase. Both Nevada's and Missouri's increases reflect projected increases in state institution populations, while West Virginia's increase reflects renewed efforts to certify state institution units. Plans for the certification of 90 new ICF-MR "beds" in Wyoming and 144 new ICF-MR "beds" in Arizona by the year 1990 represent the first entry into the ICF-MR program by these two states. With their participation all 50 states and the District of Columbia now utilize the ICF-MR program option.

Small state ICFs-MR. Small state-operated ICFs-MR are found in less than one third (13) of all states. Of these 13 states, four anticipate an increase in the number of persons in small state-operated ICFs-MR, with the most significant increase of 965 percent projected by Massachusetts. Seven of the 13 states anticipate no significant change in the number of persons in small ICFs-MR. Plans to begin utilization of small state-operated ICFs-MR for the first time were noted in four states, with 108 new small state-operated ICF-MR beds planned for in Kansas, 93 in Arizona, 60 in Alabama and 40 in West Virginia. In contrast a complete phase out of small state-operated ICFs-MR is planned by

Table 8

Projected Changes in the Population of ICFs-MR between June 30, 1987 and June 30, 1990 and Associated Factors

State	PROJECTED CHANGES: State Operated 1-15 1987	1990	Proj. +/-	State Operated 16+ 1987	1990	Proj. +/-	Nonstate 1-15 1987	1990	Proj. +/-	Nonstate 16+ 1987	1990	Proj. +/-	Factors Affecting Projected Changes: State 16+	State 15-	Nonstate 16+	Nonstate 15-
ALABAMA	0	60	60	1,308	1,210	-98	31	62	31	0	0	0	ABE			
ALASKA	0	0	0	59	59	0	34	36	2	0	0	0	C			F
ARIZONA	0	93	93	0	144	144	0	0	0	0	0	0	BC	C		B
ARKANSAS	0	0	0	1,337	1,069	-268	0	300	300	124	184	60	BCE		C	BC
CALIFORNIA	0	0	0	6,832	6,832	0	1,510	2,265	755	3,115	2,959	-156	B			BA
COLORADO	280	280	0	901	739	-162	0	0	0	346	329	-17	B		B	B
CONNECTICUT	255	255	0	953	953	0	138	145	7	17	18	1	B	B		B
DELAWARE	0	0	0	383	298	-85	61	88	27	0	0	0	AB		A	
D.C.	0	0	0	358	358	0	375	375	0	0	0	0				D
FLORIDA	0	0	0	1,277	1,277	0	0	53	53	1,875	1,781	-94	BC		AC	AC
GEORGIA	0	0	0	1,839	1,839	0	0	0	0	110	110	0	BC	C	C	C
HAWAII	8	8	0	260	115	-145	29	132	103	0	0	0	AB			AB
IDAHO	0	0	0	263	150	-113	124	149	25	58	0	-58	BC		BC	BCD
ILLINOIS	0	0	0	4,471	4,247	-224	738	1,476	738	4,191	4,191	0	BC		C	C
INDIANA	0	0	0	1,491	1,342	-149	1,984	3,000	1,016	593	1,000	407	D		D	D
IOWA	0	0	0	1,057	898	-159	52	146	94	625	656	31	CDF		C	C
KANSAS	0	108	108	1,298	974	-324	187	196	9	676	608	-68				
KENTUCKY	0	0	0	686	686	0	0	0	0	513	513	0				
LOUISIANA	33	0	-33	2,889	2,600	-289	805	885	80	1,547		-1,547	BCF	BC	BC	BC
MAINE	26	25	-1	291	226	-65	233	295	62	138	106	-32	ABE		BC	B
MARYLAND	12	12	0	1,452	1,292	-160	0	0	0	0	0	0	BD			
MASSACHUSETTS	27	235	208	3,367	3,030	-337	307	338	31	0	0	0		BE		B
MICHIGAN	0	0	0	1,658	938	-720	1,767	1,776	9	0	0	0	AB		BI	AB
MINNESOTA	28	35	7	1,653	1,041	-612	2,819	3,143	324	2,049	1,742	-307	BC	ABC	BC	BC
MISSISSIPPI	0	0	0	998	998	0	0	0	0	605	605	0				
MISSOURI	16	16	0	1,874	2,034	160	121	127	6	137	137	0	C	BC	C	CF
MONTANA	0	0	0	254	235	-19	10	10	0	0	0	0	ABC	BC	BC	BC
NEBRASKA	0	0	0	472	448	-24	0	0	0	344	310	-34	BCD	AB		
NEVADA	0	0	0	175	184	9	15	30	15	0	0	0	BI			BF
NEW HAMPSHIRE	0	0	0	190	80	-110	54	54	0	21	21	0	B		B	B
NEW JERSEY	0	0	0	3,757	3,757	0	0	0	0	72	72	0				
NEW MEXICO	0	0	0	500	500	0	133	146	13	0	0	0	BC		C	BCF
NEW YORK	1,853	2,131	278	10,022	8,268	-1,754	4,243	5,007	764	1,172	1,172	0	ACH	ACHI	C	ACHI
NORTH CAROLINA	0	0	0	2,562	2,562	0	539	659	400	402	402	0	ABI		B	AB
NORTH DAKOTA	0	0	0	398	230	-168	494	445	-49	0	0	0	BE			AB
OHIO	0	0	0	2,900	2,465	-435	1,033	1,136	103	3,758	3,570	-188	ABD		B	B
OKLAHOMA	0	0	0	1,145	710	-435	0	0	0	1,794	1,794	0	ABCE		BCE	BCE
OREGON	0	0	0	1,145	695	-450	22	27	5	219	175	-44	BC		BC	BC
PENNSYLVANIA	0	0	0	5,127	4,614	-513	441	463	22	1,960	1,969	9	ABC		BC	ABC
RHODE ISLAND	175	196	21	280	70	-210	507	613	106	32	0	-32	ABD	ABD	ABD	ABD
SOUTH CAROLINA	22	0	-22	2,534	2,154	-380	507	634	127	76	57	-19	C			
SOUTH DAKOTA	0	0	0	485	427	-58	195	0	-195	0	0	0	B			B
TENNESSEE	0	0	0	2,089	1,981	-108	12	13	1	188	188	0	B			
TEXAS	422	422	0	7,936	7,539	-397	860	1,290	430	2,685	2,685	0	CE	C	C	CE
UTAH	0	0	0	540	416	-124	30	48	18	581	523	-58	BC	C	CF	C
VERMONT	0	0	0	196	162	-34	54	51	-3	0	0	0	B		B	B
VIRGINIA	0	0	0	2,970	2,896	-74	91	93	2	108	108	0	F			F
WASHINGTON	0	0	0	1,810	1,774	-36	145	152	7	598	598	0	BCDF		BC	BCDFI
WEST VIRGINIA	0	40	40	210	254	44	194	424	230	0	59	59	BC	CE	BC	BC
WISCONSIN	0	0	0	1,868	1,401	-467	40	40	0	1,660	1,660	0	ABF		B	BD
WYOMING	0	0	0	0	90	90	0	0	0	0	0	0	AC	C	C	C
U.S. Total	2,874	3,633	759	88,424	79,165	-9,259	20,654	26,322	5,668	32,398	31,849	-549				

* + is used when new settings are being developed where none existed before and a percentage change cannot, therefore, be be completed. It represents the total projected residents.

A. Increase of community-based alternatives
B. Increase of community based alternatives via HCBS waiver,
C. Anticipation of upcoming federal legislation; restructuring of Medicaid (Chafee Home and Community Quality Services Act) or changes in Federal Medicaid policy,
D. HCFA standards (compliance with higher ICF/MR standards, stricter surveys, federal look-behind surveys, utilization reviews).
F. Budget Reductions/Constraints.
G. State Legislation.
H. Closures,
I. Waiting lists/OBRA 1987.

Louisiana and South Carolina. The majority of states (34) neither operated small ICFs-MR in 1987 nor had plans for future development.

Large nonstate ICFs-MR. Over half of all states (29) project a stable or declining number of persons in large nonstate ICFs-MR. The state of Rhode Island anticipates a complete phase out of all large nonstate ICFs-MR by 1990. A decrease of 20 to 25% is projected in South Carolina, Maine, and Oregon. Seventeen of the 29 states serving individuals in large nonstate ICFs-MR do not anticipate a change in the number of persons in these facilities. Five states project an increase in the number of persons residing in large nonstate ICFs-MR, with Indiana projecting the greatest increase of 69% by 1990. No large nonstate ICFs-MR exist in 16 states, and no plans for future development of such facilities are reported by these states.

Small nonstate ICFs-MR. Most states (36) report a stable or increasing number of persons in small nonstate ICFs-MR from June 30, 1987 to 1990. States anticipating the most dramatic rate of increase in small nonstate ICF-MR utilization include Hawaii with a projected increase of 354 percent (29 to 132 residents) and Iowa with a projected increase of 181 percent (52 to 146 residents). Vermont and North Dakota project a slight decrease in the number of persons in small nonstate ICFs-MR, while South Dakota anticipates a complete phase out of all small nonstate ICFs-MR by 1990, by replacing community ICF-MR services with services provided under the Medicaid waiver (discussed in Part IV of this report). As of June 30, 1987 there were no small nonstate ICFs-MR in 12 of the 51 states surveyed. No plans for future development are reported by ten of these 12 states, with many noting the utilization of Home and Community-Based Services as an alternative to small nonstate ICFs-MR (see Part IV). Two of these 12 states project development of new small nonstate ICFs-MR, with Arkansas anticipating 300 new residents and Florida anticipating 53 new residents by 1990.

Overall projections of ICF-MR utilization. It can be estimated that by June 30, 1990 there will be a total of 140,969 persons with mental retardation in ICF-MR certified facilities, which would represent a 2.3% decrease from the 144,350 ICF-MR residents on June 30, 1987. States project that large state-operated ICFs-MR will house approximately 79,165 persons (down 9,259 or 10.5% from

1987); small state-operated ICFs-MR will house approximately 3,633 persons (up 759 or 26.4% from 1987); large nonstate ICFs-MR will house approximately 31,849 persons (down 549 or 1.7% from 1987); and small nonstate ICFs-MR will house approximately 26,322 persons by June 30, 1990 (up 5,668 or 27.4% from 1987). If these projections hold true the trend of increased utilization of small ICF-MR will continue, with 21.3% of all ICF-MR residents in small facilities by 1990. At the same time the dominance of the ICF-MR program in state institutions will continue, with 95% of all state institution residents in ICF-MR certified units on June 30, 1990.

Factors Related to ICF-MR Utilization

State Orientation to ICF-MR Use

States differ widely in their current and projected future approach to utilization of the ICF-MR program, as is evident in the numerous statistics provided in Tables 5, 6, and 8. Among the ten case study states, ICF-MR utilization as of June 30, 1987 ranged from 28.3% of all placements in Connecticut to 87.2% in Mississippi. In both states, however, there is considerable interest in further expanding utilization of the ICF-MR option. In Connecticut the state has developed nearly 36 small ICFs-MR over the past few years, both state- and privately-operated. In Mississippi the state MR/DD agency's interest in the ICF-MR expansion has been largely thwarted by the inability to finance Medicaid matching requirements and by an overall moratorium on expansion of long-term care facility capacity. However, both states have been increasing the proportion of ICF-MR certified capacity within their large state facilities by placing priority on depopulation of noncertified units of their state institutions, as was the tendency around the country.

Among case study states the ICF-MR program is the major financial resource for residential services in Florida, Indiana, Minnesota, New York, Texas, and Mississippi. It is used extensively for both state and nonstate facilities, especially in California, Indiana, Minnesota, and New York. These four states collectively had a total of 1,733 nonstate ICFs-MR as of June 30, 1987, serving over 17,000 residents; an additional 21,881 residents were served in state-operated ICFs-MR. Their combined total

number of ICF-MR residents represented approximately 31% of all ICF-MR residents in the United States as of June 30, 1987.

Across the country states use the ICF-MR program primarily to finance residential care in large facilities, (i.e., serving 16 or more persons with mental retardation or related conditions). In fact on June 30, 1987 only four states (District of Columbia, Michigan, North Dakota, Rhode Island) had as many residents in small ICFs-MR (15 or fewer residents) as in large. This compared with 26 states which had more than half their total residential service population in small facilities (i.e., both ICF-MR certified and noncertified). However major differences exist among states which may share similar ICF-MR utilization patterns. Among the ten case study states, for example, Colorado, Florida, Mississippi, and Oregon have relatively low utilization of the ICF-MR program in smaller (15 or less) facilities. In Colorado and Oregon there have been significant efforts to reduce ICF-MR utilization in the belief that it is too restrictive for large numbers of individuals with mental retardation and related conditions and that it does not permit enough flexibility in meeting the unique needs of individual residential care clients. Colorado has used the Home and Community-based Services waiver option (see Part IV) to convert all but its state facilities and nine large private ICF-MR facilities, which are outside the control of the state MR/DD agency, to noncertified residential units. The state's total ICF-MR population dropped approximately 37.5% between June 30, 1982 and June 30, 1987 from around 2,000 to 1,247 and is expected to drop to 1,068 by June 30, 1990. Oregon has experienced no additional ICF-MR development since 1978, and has reduced its utilization of the ICF-MR program 28% in the 1982-1987 time period along with its general depopulation of state institutions. While most states have reduced ICF-MR utilization in large state facilities, relatively few have simultaneously reduced program use in small nonstate facilities.

In contrast, ICF-MR utilization in Florida has focused primarily on expanded use of the program for large private facilities, even as large state institutions were depopulated or closed. As of June 30, 1987, 1,875 residents were served in 41 large private ICFs-MR, an increase of 1,217 over the number in large private facilities as of June 30, 1982. In still another variation, Mississippi's use of the ICF-MR program almost exclusively in large facilities is associated primarily with the extremely limited number

of community residential facilities in general; specifically, as of June 30, 1987, 83% of all residential care clients were in facilities of 16 persons or more.

Despite the differences among states in their utilization of the ICF-MR program, the majority of case study states expressed concern about the restrictiveness of the program, and the limited number of persons with mental retardation and related conditions for whom the level of care required under the ICF-MR standards would represent the most appropriate or beneficial residential alternative. As indicated above, Colorado and Oregon have moved actively to discourage use of the program because of its perceived restrictiveness. Concerns in Florida have led the state to target use of its new six-bed ICF-MR program only to individuals who are nonambulatory or otherwise severely developmentally disabled. In Mississippi and Texas, however, concerns about restrictiveness have been tempered by the overall lack of services; lack of alternatives in Minnesota has also been a factor in mitigating the issue. In Indiana, the same issue has been raised by the Health Care Financing Administration, which has questioned whether substantial numbers of persons receive the ICF-MR level of care when it is unnecessary and inappropriate to do so. The state's approach is still to consider the program appropriate for individuals across a wide range of mental retardation.

Factors of Influence on ICF-MR Use

The basic factors influencing recent and projected state utilization of the ICF-MR program are generally the same as those affecting each state's overall residential care system. Significant internal factors include the increased support for expanded use of small, community-based residential programs; policies to continue depopulation of large state facilities; and the effort to provide more individualized and client-centered residential alternatives. Influences external to state MR/DD agencies affecting ICF-MR trends and projections include court actions, population growth, oversight activities of the Health Care Financing Administration, and state legislative actions affecting reimbursement rates and limitation of residential facility development. Interestingly, although these factors are common among states, states vary substantially in what implications for ICF-MR utilization they perceive as deriving from them. The factors of influence can be grouped in relation to four major considerations affecting state decisions

about the nature and amount of ICF-MR utilization: 1) economic considerations, 2) access to the Home and Community-based waiver, 3) federal reform proposals, and 4) state policy actions, as described in the following section.

Economic considerations. The basic economic consideration for most states in their utilization of the ICF-MR program is the availability of federal financial participation (FFP). In many states this is a major factor in the use of the ICF-MR program for community-based residential care, as well as the continuing financing of large state facilities. This is obviously a particularly potent consideration for states, and fear of loss of FFP through decertification of ICF-MR facilities has been a significant factor in certain state decisions regarding depopulation of large state institutions. States with public institution units which are not ICF-MR certified commonly try to maximize FFP availability by placing priority on the depopulation of the noncertified units. Despite the attractiveness of FFP, however, economic considerations in some states have focused on the difficulties in financing the state match. Among the case study states, for example, Indiana has been hesitant to increase the use of the ICF-MR program, as well as other Medicaid options, in part because of state budget concerns regarding the match requirements for what tends to be an expensive level of care. Mississippi also lacks state dollars for service development, despite the state's very favorable cost match requirement of 20.35% in FY 1988.

Most states have experienced significant cost increases in large public institutions. In some cases these increases have been highly disproportionate to cost/reimbursement rate increases in other ICF-MR facilities. Notwithstanding the higher proportion of residents with severe and multiple disabilities and the presumably higher cost of care for these individuals, concern about these cost increases has become part of the public debate about the cost-effectiveness of various residential alternatives. Factors noted as frequently associated with large cost/rate increases in state institutions include the costs of meeting active treatment and other ICF-MR certification requirements; increases in unit costs as fixed costs for such items as building maintenance remain relatively constant while the number of residents declines; and, to a lesser extent, changing personnel patterns as institutions become more heavily oriented toward specialized treatment. Wisconsin's Director of the Developmental Disabilities Office

noted that advocates of community alternatives within the state government were finding themselves in a "strange alliance" with fiscal conservatives because of the "extraordinary" increases in costs of care in the ICF-MR certified state institutions.

Some states also have experienced significant increases in costs and reimbursement rates for small nonstate ICFs-MR. For example, among the case study states costs increased considerably for individualized community ICF-MR residences for individuals with problem behaviors in Connecticut, for ten-bed community ICFs-MR in New York, and in six-bed nonstate ICFs-MR in Texas.

With respect to the rapidly growing private management of residential services, economic considerations are reflected either in limitations on the development of new capacity or in rate limitations. Efforts to contain costs through rate restrictions have been a significant factor in some states. Often the effect has been considered negative as providers felt that ICF-MR reimbursement rates lagged significantly behind actual costs and showed reluctance to enter the market or expand service capacity. For example, both California and Texas reported substantially less development of small community-based ICF-MR facilities than had been projected and desired as a direct result of delays in obtaining rate increases for small facility providers. In 1988 the California General Assembly responded to this problem with an appropriation of $12 million specifically for reimbursement rate adjustments.

Several states note economic concerns in relation to compliance with federal residential facility requirements--in particular the application of stricter ICF-MR standards and new survey methodologies. Costs associated with the retention of ICF-MR certification, although justified from the state perspective of avoidance of the loss of FFP, have raised fears in many states that these expenditures will reduce the resources available for the development of additional community-based services. Even before experience with the new ICF-MR standards a number of states have indicated that state budget constraints coupled with stricter monitoring and compliance measures under the 1974 ICF-MR standards had become a factor in the reduced use of the ICF-MR program. For example, Rhode Island, along with several other states, anticipates a reduction in the use of ICFs-MR due to the more stringent interpretation of federal regulations as well as to the availability of Home and Community-based waiver

options. Iowa reports that state budget constraints have placed limitations on new staff development which in turn have required lowering of facility census to comply with active treatment requirements. Among the case study states, Indiana reported it has significantly reduced its use of large state ICF-MR institutions as a result of HCFA oversight activities. Oregon and Colorado reported that responding to the "look behinds" of its state institutions has brought about plans of correction containing substantial depopulation. State budget restrictions in general are influential in limiting the development of small ICFs-MR in Nevada, New Mexico and Alaska.

Home and Community-Based Services waiver. The availability of the Medicaid Home and Community-Based Services waiver has been significant in providing many states with FFP that can be used to support residential services alternatives to ICF-MR care (less the cost of room and board), and, therefore, to directly reduce the proportional utilization of the ICF-MR program. Although not designed specifically as a residential services program, the waiver is used primarily to provide services to people with mental retardation and related conditions who are in supervised, community residential settings. In fact, of the 7 case study states with Medicaid waiver programs, all but Texas estimated that at least two-thirds of waiver recipients were in out-of-home residential care. The availability of the Home and Community-Based Services waiver was reported to be a direct factor of principal influence to ICF-MR utilization in three of the ten case study states (Colorado, Connecticut and Oregon). The waiver option was seen as providing states the opportunity for more flexibility and individualized residential services than the ICF-MR program. It was a factor especially in Colorado and Oregon in the significant reduction in the use of small community-based ICF-MR facilities. In Minnesota it represented an alternative model of long-term care funding following a legislative moratorium on ICF-MR development. Texas and California reported that the waiver had had relatively little effect to date on ICF-MR utilization. However, Texas anticipates considerably increased effect on ICF-MR utilization under its renewal application, which requests significantly increased capacity. The remaining state (Florida) reported the waiver to have had only a modest effect on overall ICF-MR use.

In the state survey, all but 3 states (of 35) utilizing the waiver option reported that it had assisted them significantly in promoting deinstitutionalization and/or the development of community-based services. Seventeen states noted specific direct effects of the Medicaid waiver on ICF-MR utilization, with 13 indicating that the primary effect was to obviate the need to increase ICF-MR capacity within the state and 4 states noting that the primary effect was to permit reduction of previously utilized ICF-MR capacity. Given the substantial importance of the Home and Community-Based Services waiver to states in the ICF-MR utilization decisions, the attractiveness of the program to states, and the significance of waiver program experience to consideration of current legislative proposals to reform Medicaid services for persons with mental retardation and related conditions, considerably more attention will be given to the Home and Community-Based Services option in Part IV of this report.

Federal reform proposals. The current Medicaid reform proposals before the 101st Congress (in the Senate, S. 284: The Medicaid Home and Community Quality Services Act of 1989 and in the House, H.R. 854: the Medicaid Community and Facility Habilitation Amendments of 1989), and more importantly their precursors in the 98th, 99th and 100th Congresses, have considerably affected state decisions regarding amounts and types of services to provide under the ICF-MR option. Those proposals linked long-term availability of Medicaid funding in various ways to movement of institution residents to community living arrangements. In all, 25 states in the state survey noted that previous legislative proposals of Senator John Chafee beginning in 1983 have directly entered into policy decisions. The nature of effects has varied. Montana's respondent notes that it has spurred discussions of policymakers regarding the most likely scenarios for the future and the substantially decreased role of institutions in those scenarios. In Oregon the proposals are reported to have represented public reinforcement of existing interest of the state agency in "more flexible/individualized options." The primary influence among affected states has been to support limits on the size of new facilities developed under the ICF-MR program (generally eight or fewer residents). Interestingly, states most likely to report no effect of the reform proposals are those which had made prior commitments in program development which fit within the requirements of the proposed legislation.

Changes in Medicaid policy contained in the Home and Community Quality Services Act were reported to be supported by 38 of the 51 states surveyed, despite the legislation's significant limitations on growth of federal funds for care in large institutions. It is important to note, however, that the state survey was conducted before the first draft of H.R. 854 was made public, and may therefore be considered to reflect previous proposals, in particular those of the 100th Congress. Almost all of the 38 states expressing support for these proposals report such reforms to be consistent with their long range planning and departmental philosophy, in particular increased community development and institutional depopulation. Of the 13 states that did not indicate support of the Medicaid policy contained in the Home and Community Quality Services Act, the most frequently expressed concern was the potential impact on states with large pre-existing institutional systems. For example, New York's respondent noted that state officials "anticipate adverse side effects of the restrictions on . . . institutional costs, combined with increased unit costs due to downsizing and closures/consolidation that will impact on the availability of state funds to support community services." This concern, coupled with the positive experience of states with the Home and Community-Based Services waiver, may increase the degree of state support for the H.R. 854 alternative, which makes no direct effort to reduce institutional services while continuing to offer expanded FFP for community services. However, because the state survey was conducted before this bill was introduced, no responses were obtained on what state preferences between the two bills might be.

State policy actions. States are moving proactively to influence use of the ICF-MR program over the next few years, primarily through the same general policy activities described above as factors influencing their entire residential care system. In particular states expect that specific laws and regulations will expand the use of the ICF-MR program for small facilities, and decrease its use in large facilities. For example, among the case study states regulatory factors of influence include:

- rules limiting all new ICF-MR facilities to a maximum of only five or six beds (Connecticut, Florida, Minnesota, Texas);
- prohibition against placement of any clients in facilities of more than eight beds unless "medically indicated" (Indiana);

- exemption of six-bed ICFs-MR from the state's certificate of need (CON) process (Florida); and
- establishing procedures that permit certain large ICF-MR facilities to "downsize" their programs to small, community-based ICF-MR units independent of the processes and limitations of establishing new community-based ICF-MR facilities.

Most states expect to exert considerable control in future development of the ICF-MR programs for small community-based residential facilities. Pointing out the importance of regulatory control of ICF-MR use, the Florida MR/DD agency respondent observed that the lack of such control was a significant factor in the substantial increase in large private ICF-MR facilities in Florida between 1982 and 1987.

In addition to efforts to restrict use of the program to small facilities, a few states have developed new classes of facilities to meet the needs of specific subgroups within the ICF-MR target population. For example, California has developed the ICF-DD-N program for individuals who are medically fragile. The expansion of this program will be confined to the development of small community-based facilities. But in some states the ICF-MR program is simply not seen as a desirable funding source for community services. For example, among the case study states neither Colorado nor Oregon plan to use the ICF-MR program for community residences, believing that it does not permit the kind of individualized and client-focused services that are more responsive to client needs as well as more cost-effective.

State-specific factors are expected to be a significant influence on ICF-MR projections in some states. For example, Indiana's agreement with HCFA on the reduction of inappropriate nursing home placements will continue to influence the state's use of the ICF-MR program. This general influence includes the expansion of the number of individuals in large nonstate ICF-MR facilities associated with the conversion to ICFs-MR of existing nursing home units occupied by individuals with mental retardation and related conditions. The three most commonly noted factors of potential impact on the future utilization of the ICF-MR option among the states were the interpretation of the new ICF-MR regulations, the implementation of P.L. 100-203 requirements regarding nursing home reviews, and changes in the state budget which might affect the amount of state money available to leverage federal financial participation.

Appropriateness and Quality of ICF-MR Care

The primary responsibilities for quality assurance in state MR/DD residential service systems generally include the following:

- establishment of quality standards;
- initial and periodic facility reviews (most commonly annual), usually in relation to licensure and/or certification; and
- review of residents as to the appropriateness of the type of residential care placement being utilized.

For ICFs-MR, the basic quality standards are established by HCFA, as in the recently revised Conditions of Participation for the ICF-MR program (effective October 1988). Although individual states may add or strengthen requirements, (e.g., as part of a separate state MR/DD residential care provider certification program), it is primarily the HCFA standards that are used as the basis for ICF-MR quality assurance activities. Under agreement with HCFA a state agency, typically the state Medicaid agency, has responsibility for the initial and annual reviews that determine whether or not the facility is certified to provide ICF-MR services. Additional oversight of state-operated ICFs-MR is usually provided in some way or another through the MR/DD agency. Overall quality assurance for residential facilities is most typically the responsibility of state MR/DD agencies, often through local or regional MR/DD authorities. States have generally established standards for nonstate residential care providers who receive state payments for their services, although the review and licensing processes used by states vary as to their formality and complexity. However, in the absence of a separate MR/DD facility licensing program that includes private ICF-MR facilities, a few state MR/DD agencies may have no direct oversight responsibility for private ICFs-MR. Various local and state social services agencies are also involved in many states in setting standards and monitoring quality in foster home, boarding home and other community placements of individuals with mental retardation and other developmental disabilities. This oversight includes community-based ICFs-MR in a number of states.

Appropriateness of ICF-MR placement. Reviews as to the appropriateness of the level of care for individuals in ICF-MR placements are generally the responsibility of the state health agency. Practices vary as to responsibility for level of care reviews of individuals in other facilities. Increasingly states have established systems for locally-based case management, frequently including coordination and oversight of residential and other services to people in the residential care system. Such oversight would typically include periodic reassessment of the appropriateness of the placement in relation to the individual's current program needs.

Most states generally follow the HCFA level of care criteria in authorizing and reviewing ICF-MR placements, without the use of additional state-specific criteria. A notable exception to this tendency among the case study states is Indiana, which uses an extensive system of adaptive behavior assessment. The Indiana Scale of Behavioral Development is used for determining which of the 12 levels of ICF-MR and noncertified residential care would be appropriate. New York's ICF-MR regulations also require the use of functional impairment criteria, including the level, severity, and number of functional impairments, in making ICF-MR placements. Like Indiana, New York has its own system, based on the Minnesota Developmental Programming System, for determining whether individuals meet these criteria.

In many states case managers in local MR/DD authorities or regionally assigned state case managers provide individual assessments of clients for whom residential care is requested and provide a measure of control over admissions to ICF-MR facilities. Follow-up level of care assessments (appropriateness of care reviews required under ICF-MR regulations) are most frequently carried out by state health agency personnel, although in some states these reviews may include consultation with the local case manager. An issue in several states, however (e.g., Colorado and Oregon) is the state MR/DD agency's lack of control over the placement of individuals in large private ICFs-MR. A similar issue in Florida was recently resolved when the state MR/DD program office assumed responsibility for level of care determination for placements in large nonstate ICFs-MR.

Limitation of ICF-MR placements only to people with mental retardation has also been the practice in several states, in particular states whose primary service agency is focused on mental retardation rather than on a combination of mental retardation and other developmental disabilities. Among the case study states, for example, Connecticut, Florida, Mississippi, and Texas limit ICF-MR placement primarily to people with diagnosed mental retardation. Texas regulations do permit that a person with a related condition can be placed in an ICF-MR, as long as the individual's IQ does not exceed 75. Many other states, as noted earlier, place specific restrictions on admission to large state ICF-MR certified institutions, primarily by limiting non-court-ordered admissions only to individuals with severe disabilities, multiple handicapping conditions, or severely challenging behaviors, or to persons above a certain age.

Finally, it should be noted that there is considerable variation among the states and, in some states, differences of opinion between the MR/DD and Medicaid program agencies, as to the interpretation of HCFA level of care criteria. Although there has been a general trend toward use of the ICF-MR program for people with more severely disabling conditions than are found in noncertified residential facilities, some states have continued to serve people with a wide range of level of disability in ICF-MR facilities. Particularly states with early and fairly intensive use of the ICF-MR option for community-based group homes (e.g., Minnesota, New York and Texas) find themselves today with substantial numbers of persons with mild and moderate levels of impairment in ICFs-MR. In each of these states, there is public discussion about the appropriateness of the ICF-MR level of care for many of the current ICF-MR residents with less severe impairments. This debate seems increasingly stimulated by the perceived need for ICF-MR placements for people with severe disabilities awaiting placement into community-based residential facilities.

Clearly the issue of level of care as perceived by states is more than one of mere compliance with existing level of care standards. There is a clear tension between the availability of FFP for care in ICF-MR certified facilities and a perception that people with less severe mental retardation or related conditions would benefit from less restrictive and more individualized settings than those required in the

ICF-MR program. In attempting to move away from the attractions of FFP to programs that might be seen as more appropriate states face three related challenges, each involving a number of key actors: 1) developing "more appropriate" and individualized programs for people with less severe impairments, without ICF-MR funding; 2) initiating movement of people with less severe disabilities from their current residence, and replacing those individuals with persons with more severe impairments or, perhaps more desirably, decertifying existing ICF-MR facilities, permitting current residents to remain, and creating other community-based ICF-MR units for those who require the level of care; and 3) altering the reimbursement, direct care staffing, professional consultation, and necessary supports to assure that the new program will meet the needs of the new clientele, i.e., those with the most severe disabilities. The simultaneous accomplishment of these objectives is in most states extremely challenging. States wishing to use non-ICF-MR individualized alternatives for people with mental retardation and related conditions in need of residential services face even graver challenges under current program limitations.

Current issues in quality assurance. Generally, and certainly not surprisingly, state perspectives on the primary issues affecting quality assurance in residential services focus on the tensions between cost containment goals and the desire to provide high quality services. Among the case study states, for example, the issue most frequently noted was the lack of resources to implement the desired level of quality in a climate of cost containment and frugality. In some states the state legislature has resisted rate increases to small private residential care providers, especially in states where costs appear to be less in the larger private facilities (California, Texas). Some states also face difficult choices (with philosophic ambivalence) between maintenance of basic quality in their large state institutions and the continued expansion of community-based services, within limits imposed by state budget processes. Generally, states simply have not been able to reduce state institution costs as they have reduced populations and as community services expansion has required "new money." Most of the case study states note this dilemma as substantially affecting the state's ability to deliver services of the quality that is desired.

ICF-MR survey and certification issues were raised in several states. Commonly state respondents spoke of differences in perspective between MR/DD agency staff and representatives of the state agency responsible for Medicaid facility reviews. Although improvement was noted and the different agencies were said to have more common understanding of the needs of individuals with mental retardation and related conditions than was the case some years ago, problems apparently remain, especially in states where ICF-MR facility reviews are conducted by generic long-term care facility surveyors rather than by MR/DD specialists. Concerns about the definition of active treatment, the contents of an appropriate treatment program, and the interpretation of new HCFA guidelines on compliance with active treatment requirements were noted. Although at the time of the case studies, states had little experience with the new ICF-MR regulations, the active treatment review procedures were expected to be similar to those used in "look behind" and in recent surveyor training programs.

The nature and depth of quality assurance concerns vary by facility type and from state-to-state. Some case study states are primarily concerned about maintaining or upgrading quality in their large state institutions, particularly with respect to meeting active treatment standards. In other states the primary concern was about quality in large nonstate ICFs-MR, especially in states where these facilities are not under the oversight of the state MR/DD agency (e.g., Colorado). Still other states are particularly concerned about quality in community-based nonstate residential facilities. Texas recently (October 1988) implemented a new quality assurance program that will require review and approval of all community residential care programs receiving state funds from the state mental retardation agency, but this program does not include ICFs-MR. Despite concern about the advisability of having state agencies as monitors of state-operated programs, some states reported that they found the level of direct control they have over conditions in the large state institutions actually makes it easier to affect quality there than in scattered and diverse nonstate-operated settings.

As noted in the section on state policy context, most states today increasingly equate program quality with community location. At the same time, they note a number of problems and issues that

must be addressed in assuring quality in community settings. Among the case study states these included:

- instances of potential conflict of interest in case management/program oversight provided by local MR/DD authorities who are also residential service providers (Colorado);
- observed needs for new state regulations that are more appropriate for new types of small facilities, especially those for persons with specific kinds/degrees of impairment (e.g., the ICF-DD-N designated small ICF-MR facilities serving individuals in need of nursing care in California);
- instances of lack of integration of state's developmental disabilities protection and advocacy systems and statutes into the system of sanctions against residential care providers who do not maintain quality standards (Connecticut);
- an overall shortage of residential placements which limits the opportunity to move residents from facilities which are not wholly appropriate or to reduce capacity in facilities which do not represent the desired models or quality of residential care, including large private institutions (Florida, Minnesota);
- observed need to include personnel recruitment, professional development, and retention as part of quality assurance in order to maintain qualified and experienced professional and paraprofessional staff in an era of low unemployment, high competition for health care professionals and service industry personnel, and relatively low funding (wages) in community services agencies (Indiana, Minnesota);
- need to reduce the extent to which the survey process and other licensing/regulating activities interrupts the program and flow of daily life in facilities, particularly in small facilities in which care, training and administration functions tend to be carried out by the same individuals (e.g., expanded use of variable length certification--up to 3 years as used by New York for high quality programs);
- need to reduce strict "paper compliance" and overall paper demand with personnel and survey approaches that not only assure adherence to the law, but which permit greater amounts of observation, evaluation, and consultation related to program quality and outcomes as part of the survey process (New York); and
- need to increase a sense of collegiality and shared purpose among regulators and providers including efforts to improve understanding among providers of the purpose of surveys, the specific expectations and the observations made by surveyors and how these relate to regulatory requirements and program quality (Minnesota, New York).

HCFA "Look Behinds". The Omnibus Budget and Reconciliation Act of 1981 (P.L. 97-35) included a provision giving the Health Care and Financing Administration authority for additional oversight of state Medicaid survey and certification activities, including those focused on the ICF-MR program. HCFA used its authority to "look behind" state quality assurance programs to conduct additional reviews, carried out by federal agency personnel, that could be used to monitor the

effectiveness of the state survey and certification programs in maintaining quality as defined by Medicaid standards. Relatively few look behind reviews were conducted until the mid-1980s, when HCFA responded to repeated reports of poor quality in ICFs-MR, in particular large state institutions, with the look behind initiative. Federal surveyors conducted reviews in most large ICF-MR certified state institutions in the nation, as well as many nonstate facilities, both large and small. In general, however, the look behind reviews concentrated on the larger of the facilities with 16 or more beds.

The look behind reviews in most states found numerous examples of facilities failing to meet ICF-MR standards, including several facilities with deficiencies of sufficient severity that they were threatened with decertification as ICF-MR facilities and termination from the Medicaid program. Typically the threat of termination came after resurveys indicated a failure to make improvements (corrections of deficiencies) required to retain certification. Look behind surveys in many facilities, both public and private, were also reported by the states to have become more stringent by the mid-1980s than most previous surveys (i.e., these conducted by state survey and certification agencies) had been, in part because of the emphasis on evidence that active treatment was being provided to all ICF-MR residents. Some facilities, primarily older state institutions, also were cited for numerous deficiencies related to the physical plant. Many corrections required lower ratios of residents to staff, especially among the professional staff whose availability is considered integral to the concept of active treatment as defined in the regulations. Many states were forced to increase staffing levels and/or to reduce the population of large state facilities in order to maintain ICF-MR certification, although the time constraints imposed during the look behind process made it difficult to use the depopulation strategy in many cases.

Among the case study states only California reported that recent look behind activity had not had a significant impact on residential services within the state. But the reason given by California's respondents for the lack of recent impact was, "principally because actual or threatened decertification among California institutions 10 years ago led to substantially increased staffing and quality assurance efforts that upgraded the public institutions." All the remaining states had two or more large ICFs-MR (a mix of state and nonstate) threatened with decertification; in three states a facility's failure to comply

with its plan of correction in relation to serious deficiencies of health and safety resulted in actual decertification. In almost all cases the facilities threatened or actually terminated from the ICF-MR program were large.

State perspectives on the look behind reviews were varied. Although it was described as a difficult experience, a number of case study state respondents saw it in a positive light. Some found the process helpful in improving program quality, in stimulating improvements in the quality assurance process itself, and in helping to clarify the rationale for the state's preference for community-based residential services in small facilities. Most states viewed it as a necessary effort in the interest of ICF-MR program quality. In a few of the case study states, however, the process was seen as having a largely negative effect. The criticisms in these states centered on the costliness of the required corrections and the quality and reliability of the review process itself.

To some extent cost concerns were shared by some of the states who viewed the look behinds more positively. One lasting impact of the federal reviews in some states is the reduced amount of funding available for the expansion of community-based services because of increased staffing levels and capital improvements in large state ICFs-MR. Although some states have attempted to depopulate facilities in order to meet staffing ratio targets, implementation has not generally been sufficient to meet timelines for correction of deficiencies. A related concern in some states is the inherent difficulty of meeting ICF-MR active treatment requirements in large institutions in general.

The new ICF-MR regulations. Some states apparently are not particularly concerned that implementation of the new federal ICF-MR conditions of participation will present significant problems. Among the case study states, for example, California and Mississippi do not expect major difficulties in compliance for their ICF-MR facilities that are already meeting active treatment requirements. In general, states even seem to judge the new regulations to be more congruent with the current goals for residential services than the previous standards. However, despite a tendency to see at least the intent of the new regulations in positive terms, there appears to be considerable concern in most states that implementation may present major challenges to their utilization of the ICF-MR program. Two of the

case study states expressed fears that the *majority* of their ICF-MR facilities would be threatened with decertification. But most states are waiting for additional clarification of requirements and for experience with their application by state surveyors before projecting what portion of the ICF-MR facilities could potentially be threatened with loss of ICF-MR certification. In most states the major focus of uncertainty and concern is the requirement for active treatment, including the following areas:

- assessment of compliance and interpretation of specific requirements;
- difficulties in meeting standards, especially in large facilities;
- specific application of active treatment in relation to other standards, e.g., a systematic program that promotes individual gains in client rights areas such as control over one's financial resources;
- criteria that will be applied to demonstrating that active treatment has been provided; and
- regulations that not only leave much of the evaluation of active treatment to the individual judgment of surveyors, but even encourage a "judgmental approach."

Additional concerns raised by one or more case study states included:

- potential exclusion from ICF-MR services of generally independent or semi-independent clients who are able to function with little supervision or in the absence of a continuous active treatment program;
- the possibility that many current ICF-MR residents will be found to be currently or eventually (due to effective active treatment) inappropriately placed, and may be forced out of their community-based home;
- issues related to informed consent requirements and guardianship; and
- the possible (and very costly) need to increase state facility personnel.

Overall, the states are awaiting additional clarification on specific aspects of the requirements. While states reported themselves to be somewhat apprehensive about the "details" of the standards, however, there were no major criticisms of the general intent.

PART IV: MEDICAID HOME AND COMMUNITY-BASED SERVICES

On August 13, 1981, Section 2176 of the Omnibus Reconciliation Act of 1981 (P.L. 97-35) established Medicaid Home and Community-based Services waivers. Final "waiver" regulations were published in March 1985. Under Section 2176, the Secretary of Health and Human Services was granted the authority to waive certain existing Medicaid requirements and allow states to finance certain "non-institutional" long-term care services for Medicaid-eligible individuals. The purpose of the "waiver" is to provide FFP for home and community-based services to persons who were aged, blind, or disabled or who had mental retardation or related conditions, if those individuals would remain in or be at considerable risk of being placed in a Medicaid-certified nursing home or ICF-MR in the absence of the alternative services. States are required to demonstrate cost-neutrality in their substitution of home and community-based services for institutional services for the "waiver population." In other words, Medicaid costs under the waiver may not exceed projected savings in Medicaid long-term care facility costs made possible by providing alternative services.

The non-institutional services that can be provided under the waiver include: case management, homemaker services, home health aid services, personal care services, adult day health services, habilitation services, respite care, or any other service that the state can show will lead to decreased costs for Medicaid reimbursed services. Although the waiver may not be used to pay for room and board, virtually all states that use the waiver for persons with developmental disabilities provide some form of residential service under the categories of personal care, habilitation, and homemaker services to people in supervised residential settings. Given both its flexibility and its potential for promoting the goal of community-based care and habilitation, the waiver has generally been recognized as having great potential in assisting states in the provision of community-based services as an option to institutional care.

The overriding fiscal principle in providing waiver services is that a state has to demonstrate in its waiver application that if it uses the waiver to provide non-institutional, community-based services, the total amount of state Medicaid expenditures will not exceed what would have been its total

expenditures in the absence of the waiver (i.e., the demonstration of cost-neutrality). States have used two main arguments in their waiver applications to demonstrate the required cost-neutrality: a) that existing beds will be closed (people will be deinstitutionalized) as a result of the waiver or b) that new beds will not be developed because 1) *planned* increases in ICF-MR beds will be reduced or eliminated with the waiver, or 2) *projected* increases in the number of persons needing ICF-MR services will be reduced by diverting such persons from Medicaid beds through waiver services. Most states have pursued the first argument, and have used waivers targeted to people with mental retardation and other developmental disabilities to reduce state institutional capacity or actually to close institutions. Proposed deinstitutionalization is a major aspect of most states' MR/DD waiver applications. In contrast, most waivers for elderly persons have been for services diverting currently non-institutionalized people from admission to nursing homes.

In addition to the "regular" Medicaid waiver, there is a special category of waiver authorized under Section 2176 called a "model" waiver. As with the HCBS waiver, the model waiver is designed to provide FFP to support home and community-based services for people who would otherwise require Medicaid-funded institutional care, including hospitalization. The model waiver authority was intended to address specific circumstances faced by individuals or small groups with respect to general eligibility or specific services, such as people with a particular disability in a specific geographic area, or with some other specific need or circumstance. Model waivers were originally limited to no more than 50 beneficiaries, with the maximum number extended to 200 in 1987. The model waiver application permits states to target a small number of individuals without demonstrating system-wide impacts on Medicaid expenditures of the alternative services. It is used primarily to support services to children with severe disabilities and chronic health conditions, thus extending Medicaid eligibility to children living at home who would otherwise have been eligible only while institutionalized, i.e., when their parents' income was not "deemed" available for their support.

Status of State MR/DD Medicaid Waiver Programs

Interest in the Home and Community-Based Services (HCBS) waiver has increased across the country, with 40 states either having an MR/DD waiver program, having had one at one time, or currently in the application process. Table 9 summarizes the current status of Medicaid waiver programs. Notable among the trends is the growing number of states seeking authority to offer home and community-based services, including seven states which obtained new "regular" waiver services authorization between June 30, 1987 and January 1, 1989. (One of these states, Michigan, already had a very small "model" waiver.) Also notable was the steady growth in beneficiaries among states with active waiver programs. Although the total beneficiaries nationwide increased only 2,438 persons (12%) from June 30, 1985 to June 30, 1987, 30 of the 35 states with regular or model waivers on June 30, 1987 reported increased numbers of beneficiaries since June 30, 1985. The primary reason for the relatively small total increase in beneficiaries nationally between 1985 and 1987 given the tendency of most states to show increases was the decrease of 4,348 beneficiaries in Florida. Excluding Florida from 1985 and 1987 totals, Medicaid waiver beneficiaries increased from 17,625 on June 30, 1985 to 20,252 on June 30, 1987. Statistics for 1988 (NASMRPD, 1989) indicate even more rapid growth to a total of 26,815 individuals for all of FY 1988. Including Florida total waiver recipients for FY 1988 are reported to be 29,446.

Nationwide, between 1982 and 1988 state Medicaid waiver programs accounted for virtually all of the approximately 22% growth in beneficiaries of Medicaid long-term care services for persons with MR/RC. Among Medicaid funded alternatives for community-based services between 1982 and 1988, total waiver service recipients increased by about 28,000, while small ICF-MR residents increased by about 18,000. This statistic suggests a general preference among states for serving individuals from an array of home and community-based services rather than facility-based (ICF-MR) services.

Cost has clearly been an important factor in the growing popularity of Home and Community-Based Services. Cost statistics are shown in the far right column of Table 9. The average Fiscal Year 1987 expenditure per beneficiary on June 30, 1987 was $12,900. This compares very favorably with

an average cost of nearly $39,000 per ICF-MR resident for Fiscal Year 1987 even when taking into account SSI benefits typically used to pay the room and board costs of Home and Community-Based Services recipients. Among the ten case study states, all but one (New York) is either currently participating in the waiver program (California, Colorado, Connecticut, Florida, Minnesota, Oregon, and Texas) or planning to apply (Indiana and Mississippi). All of the currently participating states have either just renewed their waiver or are in the process of doing so; none plans to discontinue its use of the waiver.

Table 9 also shows state utilization of the services most commonly authorized for persons with mental retardation and related conditions. States universally offered habilitation services as part of their waiver, including day habilitation programs, residential-facility based training, behavioral intervention services, and early intervention services (3 states requested authorization for services which were clearly habilitative in nature under categories other than "habilitation"). Respite care was authorized for 83% of states with waiver services programs. Case management and personal care, including direct care in residential settings, were authorized for 80% of states requesting waivers. Transportation was approved for a third of applicants.

Most of the case study states are providing home and community-based services to people with relatively severe developmental disabilities in out-of-home supervised residential settings, similar to waiver utilization across the nation. The waiver is seen as a significant component of the state's residential care system in each of the case study states with an approved program. It has been a major factor of influence in Colorado, Connecticut, and Oregon. Colorado, for example, credits the waiver with permitting the state to continue its expansion of community services at a time of severe state budget constraint. Although Minnesota's growth in community-based residential services was somewhat slower than anticipated due to delays in the response of local (county) MR/DD authorities to use the waiver, by mid-1988 the Medicaid waiver represented Minnesota's second largest category of service for supporting the daily living of persons with mental retardation and related conditions. It has surpassed the use of state institutions and is second only to provision of services in private ICFs-MR.

Table 9

Medicaid Waiver Utilization for Persons with Mental Retardation/Developmental Disabilities

State	Type of Waiver (6/30/87)		Persons Served 6/30/1987	New Reg. After 6/30/87	Change 6/30/85 to 6/30/87	Services Authorized in State Waiver Programs						FY 1987 Expenditures	FY 1987 Expenditures per 6/30/87 beneficiary
	Regular	Model Only				Case Management	Habilitation	Personal Care 1	Respite Care	Transportation	Other		
ALABAMA	X		1,570		89		X					$6,422,136	$4,091
ALASKA			0									0	0
ARIZONA			0									0	0
ARKANSAS			0	X		X	X	X	X	X	X	0	0
CALIFORNIA	X		3,027		-47	X	X	X	X	X	X	$42,499,490	$14,040
COLORADO	X		1,389		220	X	X	X	X	X		$18,015,808	$12,970
CONNECTICUT			0	X		X	X	X				0	0
D.C.			0									$851,320	$10,510
DELAWARE	X		81			X	X	X	X		X	0	0
FLORIDA	X		2,631		-4,348	X	X	X	X	X	X	$11,636,198	$4,423
GEORGIA			0	X			X	X	X		X	0	0
HAWAII	X		56		24	X	X	X	X		X	$541,453	$9,669
IDAHO	X		55		12		X					0	0
ILLINOIS	X		664		167	X	X		X			$11,732,072	$17,669
INDIANA			0									0	0
IOWA		X	4		4		X	X	X		X	0	0
KANSAS	X		135		35	X	X	X	X		X	0	0
KENTUCKY	X		609		120	X	X	X	X		X	$12,011,692	$19,724
LOUISIANA			0									0	0
MAINE	X		400		88	X	X	X	X	X		$6,545,325	$16,363
MARYLAND	X		685		306	X	X	X	X	X		$25,265,368	$36,884
MASSACHUSETTS	X		593		154	X	X	X	X	X	X	$3,819,886	$6,442
MICHIGAN		X	3	X	3		X					$79,817	$26,606
MINNESOTA	X		1,423		1,181	X	X	X	X		X	$13,382,535	$9,404
MISSISSIPPI			0									0	0
MISSOURI			0	X			X	X	X	X	X	0	0
MONTANA	X		210		24	X	X	X	X	X	X	$4,131,497	$19,674
NEBRASKA			0	X		X	X					0	0
NEVADA	X		134		-25	X	X				X	$1,541,640	$11,951
NEW HAMPSHIRE	X		541		131	X	X	X				$13,129,066	$24,268
NEW JERSEY	X		2,596		733	X	X	X	X			$27,220,654	$10,486
NEW MEXICO	X		220		171	X	X	X	X		X	$1,043,690	$4,744
NEW YORK			0									0	0
NORTH CAROLINA	X		328		215	X	X	X	X		X	$3,129,625	$9,542
NORTH DAKOTA	X		724		325	X	X	X	X			$6,543,006	$9,037
OHIO		X	100		100	X	X	X	X	X	X	$660,971	$6,610
OKLAHOMA	X		70		702		X	X	X			$516,333	$7,376
OREGON	X		832		400		X	X	X	X	X	$8,782,610	$10,556
PENNSYLVANIA	X		1,203		1,093	X	X		X	X	X	$35,639,570	$29,626
RHODE ISLAND	X		136		-100	X	X	X	X		X	$5,626,975	$41,375
SOUTH CAROLINA			0									0	0
SOUTH DAKOTA	X		596		142	X	X	X	X	X	X	$6,380,740	$10,706
TENNESSEE	X		213		213	X	X	X	X			$1,824,975	$8,568
TEXAS	X		70		52	X	X	X	X		X	$1,750,024	$25,000
UTAH			0	X								0	0
VERMONT	X		196		44	X	X	X	X			$4,785,690	$24,417
VIRGINIA			0									0	0
WASHINGTON	X		886		-39	X	X	X	X		X	$13,503,374	$15,241
WEST VIRGINIA	X		124		124	X	X	X	X		X	$863,024	$6,960
WISCONSIN	X		190		125	X	X		X		X	$3,424,404	$18,023
WYOMING			0									0	0
U.S. Total	32	3	22,694	7	2,438	32	40	32	33	13	25	$293,783,920	$12,948
						(80%)	(100%)	(80%)	(83%)	(33%)	(63%)		

1. Includes general direct care services in residential settings.
2. Kansas and Oregon officials were only able to estimate waiver recipients on 6/30/85 due to "multi-categorical" services.

Summary of Case Study States

The seven case study states with active waivers vary to some extent as to number of clients served, comparison between number served and number approved, target population characteristics, and the effects of the waiver on the state's use of the ICF-MR program. Briefly summarized below is each of these state's experience in providing Home and Community-Based Services through the Medicaid waiver.

California is completing its sixth year of waiver activity. A renewal application is currently in process. As of October 1988, 2,518 clients were receiving services through the waiver; the approved maximum is 3,360. California has recently stimulated more participation in the waiver by providing additional funds to the regional MR/DD authorities for administrative costs. The waiver is targeted to individuals with the most intensive level of care requirements. Ninety-seven percent of waiver participants are in residential care placements.

Colorado is in its seventh year of its HCBS waiver, having recently (fall 1988) submitted its renewal application. The state hopes to raise its authorized number of persons to be served from its present level of 2,000; approximately 1,600 people are currently receiving waiver services. Colorado's waiver is targeted to individuals with severe or profound mental retardation or, if moderately retarded, with significant adaptive behavior needs. Approximately two-thirds of the waiver clients are in supervised residential care placements.

Connecticut is in its second year of the waiver, and plans to renew in 1990. In October 1988 the waiver was at full authorized utilization with 650 persons receiving services, with about 1,200 anticipated by mid-1989. The waiver is not targeted to any particular level of disability, however, 100%* of the participants are in residential placements.

Florida is in its sixth year of the waiver and has recently completed (Fall 1988) a five-year renewal. The waiver is at full capacity with 2,631 persons receiving services. The waiver's target population is clients with the highest level of need and those who are the costliest to serve. All waiver service recipients are in supervised residential settings.

Minnesota is in the fifth year of its waiver program and the second year of a five-year renewal. The waiver was serving 1,579 individuals in October 1988, which was considerably less than approved capacity of 2,360 for Fiscal Year 1989. Targeting of the waiver is mixed, as utilization of the waiver is on a county-by-county basis associated with individual county quotas. It is estimated that 80% of the participants are in residential placements.

Oregon is in its seventh year, and has just completed its renewal. Oregon's waiver is at full capacity of 1,000 beneficiaries. Waiver services are targeted to individuals with the highest needs and highest costs to serve. All waiver service recipients are in supervised residential settings.

Texas is in the third year of its first waiver application and is in the process of submitting its renewal. Approximately 350 people were being served as of October 1988; the waiver's maximum approved level is 450. The renewal application requests an increase to 1,350 beneficiaries. Waiver services are not targeted to clients with any particular characteristics other than mental retardation. Approximately 53% are in residential care settings.

Table 10 illustrates the basic features of each case study state's Home and Community-Based Services waiver.

Future waiver option use. All of the case study states currently participating in the Home and Community-Based Services waiver program (i.e., California, Colorado, Connecticut, Florida, Minnesota, Oregon and Texas) plan to continue. All seven have either renewed their MR/DD waiver recently or are in the process of doing so. The majority are seeking an expansion in the waiver's capacity. States not serving at the level of the currently approved number of individuals are promoting expansion of its use through technical assistance and education of local authorities.

Most of the participating states see the waiver as an important element in their efforts to continue expansion of community-based services, including the support of residential care. Although waiver funds cannot be used directly for room and board, states plan to continue using the option to support residential services and supports that are described by the various categories of services available through the waiver, principally habilitation, personal care, and/or homemaker services.

Table 10

Medicaid Waiver Status of Case Study States as of October 1988

State	Number of Years	Renewal Status	Number of Partic. Approved	Number Being Served	Target Population	Percentage in Non-Family Res. Care	Number of Partic. as Percentage of No. in Res. Care	Other Comments
CA	6th Year	In process	3,360	2,518	Intensive level-of-care	97%	11.6%	Encouraging increased local participation; Minimal effect on ICF-MR
CO	7th Year	Just renewed	2,000	1,500-1,600	Severely/profoundly MR or moderately MR with signif. adaptive behavior needs	67%	52.6%	Want to raise cap on number of participants; Signif. impact on ICF-MR/all small converted
CT	2nd Year	Plan to renew in 1990	650	650	No particular characteristics	100%	13.5%	Deterrent to future ICF-MR development
FL	6th Year	Just renewed (5 year)	2,631	2,631	Clients with highest needs/highest costs	80%	32.1%	Some effect on ICF-MR, including closure of 60 bed PRF and diversion
IN	NA							
MN	5th Year	2nd Year of 5-year renewal	2,360	1,579	Mixed/related to individual county quotas under consent decree	80%	18.0%	Quotas plus % cap are disincentives to serving more severely disabled clients
MS	NA							
NY	NA							
OR	7th Year	Just renewed	1,000	1,000	Clients with highest needs/highest costs	100%	31.8%	Deterrent to ICF-MR development
TX	3rd Year	In process	450	348	No particular characteristics	53%	2.7%	Minimal effect on ICF-MR to date; Renewal application seeks increase to 1,350

Generally states plan to continue and in some cases expand targeting of their waivers on individuals with the most severe disabilities and whose noninstitutional services "packages" are the most costly (California, Colorado, Florida, Oregon). States clearly expect the waiver to be a significant factor in their expansion of efforts to serve such individuals in small client-focused settings that provide maximum opportunities for community interaction (California, Minnesota) and cost-effective service plans that are tailored to meet individual needs rather than facility requirements (Colorado, Florida, Minnesota, Oregon).

Effects of waiver on other services. A primary significance of the waiver program has been as a resource for the expansion of community-based services such as habilitation and support services to people in non-Medicaid funded residential situations, including the family home for some individuals. Prior to availability of this funding, federal funds for community-based programs of persons not living in ICFs-MR came primarily from Title XX of the Social Security Act. In 1981, the same Omnibus Budget Reconciliation Act (P.L. 97-35) that created the Home and Community-Based Services waiver converted Title XX to the "Social Services Block Grant" (SSBG) program. This amendment to Title XX gave states greater latitude to spread (fewer) funds over a broader range of services. States welcomed the alternative funding available through the waiver, in part because of the reduced federal support of community-based programs for persons with mental retardation and other developmental disabilities available through the SSBG program.

But the attractiveness of the waiver to states involves much more than availability of FFP. Case study states consistently note its congruence with the evolving goals of state MR/DD services systems. Two aspects of waiver services are of particular interest in this regard: (1) the emphasis on client-centered rather than facility-based services, and (2) the support for and demonstration of successful programs of working with persons with the most severe and challenging developmental disabilities in small community settings.

Residential services and supports. The waiver is not generally thought of as a residential service program because it cannot be used for room and board, and because of its basic goal of providing an alternative to institutional care (i.e., ICF-MR services, in the case of individuals with mental

retardation and related conditions). However, states definitely use it widely to support residential care. As illustrated in the summaries of case study states in Table 10, in six of the seven case study waiver states (all but Texas), a substantial majority of waiver beneficiaries were in residential placements providing non-family supervision (all but Texas which had about 53% out-of-home). Percentages in the other states ranged from 67 percent in Colorado to 100 percent in Connecticut and Oregon.

Effects on ICF-MR utilization. Nationwide, between 1982 and 1988 state Medicaid waiver programs accounted for virtually all the approximately 20% growth in beneficiaries of Medicaid long-term care services for persons with MR/RC. This is a compelling statistic which suggests a general preferability among states of a comprehensive array of home and community-based services to a facility-based (ICF-MR) model for expanding community-based services. Even though as a means of supporting community-based services, small ICF-MR increases between 1982 and 1988 were about 70% as large as the increases in home and community-based services (about 17,750). The waiver option has generally provided the case study states with a substitute for increased ICF-MR development. Even in states where ICF-MR growth has continued (California and Florida), utilization of Medicaid Home and Community-based Services is reported to have slowed what would have otherwise been the rate of ICF-MR expansion. It has also been a deterrent to ICF-MR development in Connecticut and Oregon. Oregon, like Colorado, has used the waiver extensively as an alternative to small community-based ICFs-MR. As described above, Colorado has converted all of its small nonstate ICFs-MR to noncertified residential programs supported by the waiver. Two of the participating case study states, Florida and Minnesota, also have used the waiver to assist them in closing large state facilities. On the other hand, the ICF-MR programs in California and Texas are reported to have been affected only minimally by the state's participation in the waiver program. In both states, however, the number of waiver recipients is relatively small in comparison to the total number of people in residential care (11.6% and 4.5%, respectively); in contrast, the number of waiver recipients in Colorado is more than half the number of people in supervised residential placements, and more than 30% in Florida and Oregon.

A majority of states in the national survey noted that the Medicaid waiver played a significant role in their continuing trend toward smaller community living arrangements. States expressed these accomplishments in terms of: 1) reduction of state institution capacity; 2) reduction of all large ICF-MR capacity; and 3) reduction of total ICF-MR capacity. Twelve states reported that state institution depopulation efforts have been enhanced by the waiver by both avoidance of institutionalization or reinstitutionalization and by actual reduction of institution capacity. Four states specified that the primary impact had been in the decreased utilization and development of large ICFs-MR. Thirteen states reported that they used the Home and Community-Based Services waiver to offer residential and community service options which discourage the utilization and development of ICFs-MR of any type. Other states focused on how the waiver generally permitted them to develop a more comprehensive and flexible array of services. Nine states reported that because the waiver offers a broader base of community service options, it has allowed for more flexibility and individualization in the provision of residential and community services. Several states report that these service options have also helped maintain more children in their home environments, by giving families alternatives to out-of-home placement. Wisconsin noted that the waiver has been instrumental in reducing nursing home populations, offering an alternative to developing new ICFs-MR to relocate people with developmental disabilities from nursing homes.

According to three states, the waiver has encouraged the movement of individuals toward less restrictive living arrangements by facilitating the transition of residents from ICFs-MR with 15 and fewer beds to other community-based alternatives, thereby allowing for the movement of other residents from larger to smaller community ICFs-MR. Both Pennsylvania and Utah report considering this Medicaid option as a more flexible alternative to ICFs-MR for gaining federal financial participation for serving their citizens in community programs. The option of responding flexibly to individual needs without federal participation is seen as administratively ideal, but financially impossible.

Only six states surveyed (35 of which had waiver programs at the time of the survey) reported that the waiver had no impact on ICF-MR utilization. Two of these six states (Kentucky and Texas)

specified that the impact of the waiver on ICF-MR utilization has been minimal due to the small number of individuals served in the waiver program compared to the current need for both waivered services and ICF-MR services. However, both states saw the waiver program as an important addition to their services systems. Kentucky notes that all ICFs-MR in their state continue to have waiting lists, despite over 600 "diversions" now receiving waiver services.

Table 11 shows the state utilization of the Medicaid waiver option along with ICF-MR utilization by the various states. It also summarizes state responses to a question regarding the effects of Medicaid waiver available on ICF-MR utilization which were described above. Obviously, grouping Medicaid waiver service recipients and small ICF-MR residents into a category of community beneficiaries presents current Medicaid programs as considerably more community oriented than the ICF-MR program alone. It shows that 28% of combined ICF-MR and waiver service recipients were in community settings on June 30, 1987, compared with 14% of ICF-MR residents only. Table 11 shows that 11 states had over one-half of their ICF-MR and waiver recipients in small community residential facilities or in their own homes.

Perceived strengths and weaknesses: States using waivers. The consensus among the seven case study states currently participating in the HCBS waiver program is that there are three major strengths in relation to state MR/DD program goals:

- Flexibility: the ability to tailor services to meet individual needs, with the resulting increased program benefits to the client;
- Federal financial participation: states are struggling to finance community-based services and the federal cost sharing assistance is important to making state dollars go further and to serving more people; and
- Compatibility: the waiver program fits well with the goals and values of contemporary service delivery philosophies.

The waiver program is seen as effective by the states because of these three factors. It permits states to gain FFP while providing less costly, individualized community-centered services, rather than relatively expensive, standardized facility-based services. Three of the case study states also noted the

Table 11

Beneficiaries of Medicaid Waiver and ICF-MR Services for Persons with Mental Retardation on June 30, 1987

State	State has Waiver Services	Number Receiving Waiver Services on 6/30/87	Total Medicaid Recipients (ICF-MR + Waiver)	Total Small Community ICF-MR (1-15) Recipients on 6/30/87	Total Community Medicaid (Waiver + ICF-MR 15)	% Medicaid Beneficiaries in the Community	How has the availability of the HCBS Waiver affected ICF-MR Utilization
ALABAMA	Y	1,570	2,909	31	1,601	55.0%	1, 2
ALASKA	N	0	93	34	34	36.6%	
ARIZONA	N	0	0	0	0	N/A	
ARKANSAS	N	0	1,495	0	0	.0%	5, 5b
CALIFORNIA	Y	3,027	14,484	1,510	4,537	31.3%	2, 5b
COLORADO	Y	1,389	2,636	0	1,389	52.7%	
CONNECTICUT	Y	0	1,363	393	593	28.8%	5
DELAWARE	Y	81	525	61	142	27.0%	7
D.C.	N	0	633	375	375	59.2%	
FLORIDA	Y	2,631	5,783	0	2,631	45.5%	3
GEORGIA	N	0	1,949	0	0	.0%	5
HAWAII	Y	56	353	37	93	26.3%	3
IDAHO	Y	55	500	124	179	35.8%	5
ILLINOIS	Y	664	10,064	738	1,402	13.9%	3
INDIANA	N	0	4,068	1,984	1,984	48.8%	
IOWA	Y	4	1,738	52	56	3.2%	
KANSAS	Y	135	2,296	187	322	14.0%	
KENTUCKY	Y	609	1,808	0	609	33.7%	
LOUISIANA	N	0	5,274	838	838	15.9%	4
MAINE	Y	400	1,088	259	659	60.6%	4
MARYLAND	Y	685	2,149	12	697	32.4%	3
MASSACHUSETTS	Y	593	4,291	331	924	21.5%	
MICHIGAN	Y	3	3,428	1,767	1,770	51.6%	5, 8
MINNESOTA	Y	1,423	7,972	2,847	4,270	53.6%	5
MISSISSIPPI	N	0	1,603	0	0	.0%	
MISSOURI	N	0	2,148	137	137	6.4%	
MONTANA	Y	210	475	10	220	46.3%	1, 2, 6
NEBRASKA	N	0	816	0	0	.0%	1, 7
NEVADA	Y	129	319	15	144	45.1%	6
NEW HAMPSHIRE	Y	541	806	54	595	73.8%	3, 5
NEW JERSEY	Y	2,596	6,425	0	2,596	40.4%	
NEW MEXICO	Y	220	886	133	353	39.8%	7
NEW YORK	N	0	17,290	6,096	6,096	35.3%	
NORTH CAROLINA	Y	328	3,555	259	587	16.5%	2, 5
NORTH DAKOTA	Y	724	1,616	494	1,218	75.4%	1, 6
OHIO	Y	100	7,791	1,033	1,133	14.5%	1, 6
OKLAHOMA	Y	70	3,009	0	70	2.3%	1
OREGON	Y	832	3,218	22	854	38.5%	1, 6
PENNSYLVANIA	Y	1,203	8,740	441	1,644	18.8%	6, 7
RHODE ISLAND	Y	136	1,130	682	818	72.4%	6
SOUTH CAROLINA	N	0	3,139	529	529	16.9%	
SOUTH DAKOTA	Y	596	1,276	195	791	62.0%	3, 5, 5b
TENNESSEE	Y	213	2,502	12	225	9.0%	5b
TEXAS	Y	70	11,973	1,282	1,352	11.3%	
UTAH	N	0	1,151	30	30	2.6%	2, 3, 7
VERMONT	Y	196	446	54	250	56.1%	5
VIRGINIA	N	0	3,171	91	91	2.9%	
WASHINGTON	Y	886	3,439	145	1,031	30.0%	1, 6
WEST VIRGINIA	Y	124	528	194	318	60.2%	
WISCONSIN	Y	190	3,758	40	230	6.1%	5, 5b
WYOMING	N	0	0	0	0	N/A	
U.S. Total		22,689	167,109	23,528	46,217	27.7%	

1. Increases use of smaller community living arrangements.
2. Avoidance of institutionalization or reinstitutionalization.
3. Allows for reduction of institutional beds.
4. Allows for the transition of clients from 15- bed facilities to community-based alternatives allowing for the transition of clients from 16+ facilities to community homes.
5. Discourages use and development of ICFs-MR in general.
5b. Discourages use and development of large ICFs-MR.
6. Allows for more flexibility and a broader base of community service options.
7. Has provided enhanced resources by increasing FFP in community-based alternatives.
8. Has offset placement of children.

waiver's contribution to the enhancement of the overall quality and completeness of their community-based services. These states cited the waiver services concept and its application in their states as the ideal model for organizing and delivering individually oriented, appropriate services for their citizens with developmental disabilities.

Not surprisingly, given the general enthusiasm for the waiver option, the major weakness of the waiver program from the participating states' perspective is its "cap" on expenditures. Some states are currently seeking waiver renewals that include significant expansion of the number of individuals permitted to be served. A number of participating states, including some currently serving fewer than approved capacity, feel there is clear overall cost effectiveness to the approach in comparison to ICF-MR or other institutional care, but that the current restrictions that tie capacity and available FFP directly to actual costs of institutional services prevent the full potential of the approach to be realized. Most would simply like to have the waiver option made a general Medicaid option without a link to ICF-MR utilization or costs, because of the overall effectiveness of this approach.

A variety of administrative issues were seen as weaknesses of the program by some of the participating states. One state felt its participation has been made more difficult by what it perceives as "shifting rules" from HCFA; another state noted problems in having to fit people into HCFA's definition of "at risk for institutionalization." Despite its attractiveness as a model approach for quality in community-based services, one state observed that quality assurance, or the lack thereof, for waiver services is a problem. The HCFA application process and ongoing administrative relationships are still seen as a problem in a few states; administrative problems in some states are also occurring between the state and local level. Administrative issues are currently being addressed by individual states in various ways. For example, one of the three states that was concerned about the limited local level participation in the waiver program found that increased reimbursement to the local MR/DD authorities for administrative expense spurred utilization. Another established information and technical assistance sessions for local governments to promote their application for and utilization of available resources.

Strengths and weaknesses: States with no current waiver. The two case study states who are currently not participating in the waiver program but planning to apply (Indiana and Mississippi) are in agreement with the currently participating states as to the importance of flexibility and federal cost-share that can be used for "client-centered" services in community settings. Both also agree that the cost-neutrality requirement is a problem. The requirement that waiver expenditures be matched 1:1 with reduction in ICF-MR expenditures is seen by New York as the major impediment to its participation. Its Director of Policy and Planning, Office of Mental Retardation/Developmental Disabilities, reports the state does not intend to apply for a waiver unless provisions are changed to permit gradual expansion of FFP and more state discretion in who and how many will be served.

Both Indiana and Mississippi share additional concerns that have been factors in their decision not to participate in the waiver program to date. In both states there has been a reluctance until relatively recently to use Medicaid programs in general. In the past five years, Indiana has greatly expanded participation in the ICF-MR program, especially to fund smaller community-based facilities. However, both states report a historical resistance among policymakers to placing state programs under federal oversight and control. It is reported to remain a concern in Indiana, no doubt compounded by the state's negotiations with HCFA the past few years in relation to nursing home placements and "look behind" findings. In both states there is a continuing issue about obtaining state resources for Medicaid matching funds. This is particularly acute in Mississippi, where even the attractiveness of a state cost-share of only about 20% of Medicaid expenditures has not been a sufficient incentive to increased Medicaid participation in the face of major state budgetary shortfalls.

In part influenced by the aforementioned concerns, the waiver application in Indiana will be limited to family and community-based services for fifty individuals with autism. The request was authorized by the Indiana state legislature specifically in relation to that target population. The state Medicaid agency has indicated that the application therefore will be limited accordingly, rather than expanded to include people with other developmental disabilities or a higher number. Indiana hopes to begin services under its waiver by mid-1989. Plans for Mississippi's waiver request are less well

defined, although the state MR/DD agency has included a waiver line item in its 1989-90 budget request. Specific numbers of individuals and target populations have not been identified as yet and there is some concern that the current low reimbursement rates for ICF-MR services in the state institutions ($60.45 per resident per day in FY 1987) will make it difficult to serve substantial numbers of individuals and/or individuals with more extensive needs with non-congregate care services under the waiver. The primary concern, however, continues to be the lack of state resources to cover the required state Medicaid match. As noted, New York has no plans to apply for a waiver, but is in the process of obtaining a Section 1115 Medicaid demonstration waiver that will permit experimentation with an alternative approach to funding MR/DD community services.

Targeting waiver recipients. Four of the seven case study states participating in the waiver program (California, Colorado, Florida and Oregon) target services to clients with the most intensive--and most expensive--service needs. A fifth state, Minnesota, would prefer to serve a greater proportion of individuals with severe disabilities under the waiver, but has been unable to because of court mandated county placement quotas and a specific dollar cap on waiver services (about $67 per day). In contrast, both Connecticut and Texas have not targeted the waiver program to people with severe disabilities, but rather are serving a wide range of individuals with mental retardation.

Overall, case study states report relatively few differences between waiver recipients and residents of ICFs-MR, although the specific beneficiary profiles vary among states. Waiver service recipients in California and Colorado are reported to have similar characteristics to those in large state ICFs-MR (i.e., severe and multiple disabilities and intense service needs). Waiver beneficiaries in Florida are generally similar to residents of large state institutions, but with fewer having serious medical problems. Waiver recipients in Connecticut and Texas have similar characteristics to ICF-MR residents. In both states, however, the waiver program and ICFs-MR both serve people with widely varying degrees of mental retardation and related impairments. Minnesota's waiver recipients tend to have less intense service needs than most of the state's ICF-MR residents as a result of county discretion regarding to whom services will be provided and the related limited funding available for waiver services per recipient.

PART V: PERSONS WITH MENTAL RETARDATION IN NURSING HOMES

Background

The Omnibus Reconciliation Act of 1987 (P.L. 100-203) provided restrictions on the circumstances under which persons with mental retardation and other developmental disabilities can be placed in Medicaid reimbursed nursing facilities (i.e., Skilled Nursing Facilities [SNFs] and Intermediate Care Facilities [ICFs]). This legislation followed over a decade of expressed concern about the appropriateness of nursing homes as residential environments for people with mental retardation by advocates such as the Association for Retarded Citizens-US (National Association for Retarded Citizens, 1975). The restrictions on nursing home placements in P.L. 100-203 stipulate that individuals with mental retardation and other developmental disabilities placed in nursing homes must require the medical/nursing services offered, and that, in addition, the facility must assure that the individual's needs for active treatment are being met. Current residents not in need of nursing services must be moved to "more appropriate" residential facilities. An exception is provided in the case of individuals who have resided in a specific nursing home for at least 30 months, who nevertheless must be given the choice of moving to a more appropriate residential setting.

A comprehensive 1985 statewide assessment of the habilitation, medical, and behavioral needs of about 2,650 persons with developmental disabilities in over 300 ICF and SNF certified nursing homes in Illinois documented concerns raised by HCFA and others by finding that only 10% of the nursing home residents with mental retardation required services warranting continued placement in an ICF or SNF (Uehara, Silverstein, Davis, & Geron, in press). These and other policy and program reviews culminated in the Congressional concern expressed in P.L. 100-203.

Relatively few data sources exist on the number or characteristics of individuals with mental retardation and related conditions in nursing homes. Estimates from the primary data sources available indicate that approximately 2.7 percent of nursing home residents have a primary diagnosis of mental retardation. The most recent survey was the Inventory of Long-Term Care Places (ILTCP), constructed by the National Center for Health Statistics and the U.S. Bureau of the Census, which included a total

of approximately 26,000 nursing and personal care homes (Sirrocco, 1988). Of these, the 8,300 homes indicating one or more residents with mental retardation reported a total of 39,527 such residents. However, because ILTCP gathered only aggregated, facility-level data, it can only be used to count the number of persons with mental retardation in nursing homes of different sizes and types, without reference to individual characteristics or services received. It does, however, allow a breakdown of facilities and residents on a state-by-state basis.

The National Nursing Home Survey (NNHS), conducted most recently in 1977 and 1985, is based on a sample of individuals in nursing homes. It provides a considerably more comprehensive picture of persons with mental retardation and related conditions in nursing homes, although this "picture" is based on relatively few people. Specifically the NNHS population estimates regarding mentally retarded residents of nursing homes in 1985 were based on a subsample of only 144 persons among the total sample of 5,200 nursing residents. However, the 1985 population estimate of 40,539 persons with a primary diagnosis of mental retardation in nursing facilities is sufficiently close to the census figure of 39,527 obtained in the ILTCP for 1986 to suggest reasonable reliability in the NNHS population estimates. An important limitation of the National Nursing Home Survey is that it permits no state-by-state population estimates.

Total Residents with Mental Retardation

The 1986 Inventory of Long-Term Care Places (ILTCP) was carried out by the U.S. Bureau of the Census for the National Center on Health Statistics. It asked respondents from all known nursing, personal care, and residential facilities in the United States that were providing long-term care to persons who were elderly/disabled or who had mental retardation or related conditions to report the total number of people with mental retardation in those facilities. Data were therefore gathered on the number of people with mental retardation in nursing, personal care, and other residential settings primarily serving elderly/disabled populations as well as those which were primarily mental retardation facilities. Facilities for elderly/disabled populations were further distinguished as nursing homes and personal care homes. "Nursing homes" included facilities which were ICF or SNF certified, or which

reported themselves to provide *routine* medical or nursing care. This latter group of noncertified nursing homes made up only 7.4% of the total nursing home beds. Other facilities were defined as "personal care facilities," because a significant majority provided personal care, although some of the facilities in the "personal care" group provided only board and supervision. In general, nursing homes had an average total size of 84 residents. Personal care homes averaged 19 residents.

As shown in Table 12, a total 39,528 persons with mental retardation were identified as being nursing/personal care home residents. These persons were residents of a total of 8,094 separate facilities. In other words, there was an average of fewer than 5 residents with mental retardation per nursing/personal care home with one or more residents reported to be mentally retarded. Fewer than one-third of the 25,646 nursing/personal care homes on the ILTCP reported any residents with mental retardation. A total of 5,702 nursing homes reported a total of 30,900 residents with mental retardation (an average of 5.4). A total of 2,392 personal care facilities reported a total of 8,628 residents with mental retardation (an average of 4.9). Nursing home/personal care home operators in 18 states reported 1,000 or more individuals with mental retardation in their homes, including eleven states in which nursing home operators (i.e., excluding personal care homes) reported 1,000 or more residents with mental retardation in the state.

Nursing/personal care home residents with mental retardation represented a relatively small proportion of people with mental retardation in residential care: only 13.4% of the total reported number of persons with mental retardation in nursing/personal care homes *and* mental retardation facilities combined. However, in six states more than one-quarter of these residents were in nursing/personal care homes according to the ILTCP.

People with mental retardation represent a relatively small proportion of the overall nursing home population. Based on estimates from the 1977 National Nursing Home Survey the population of persons with a *primary* diagnosis of mental retardation was 3.4% of the estimated total nursing and personal care home population (1,303,100); in 1985 it was 2.7% of an estimated 1,491,400 persons in the total population (an additional 42,000 people had mental retardation reported as a nonprimary condition).

Table 12

Number of Residents in Nursing and Personal Care Homes Reported to be Mentally Retarded by State in 1986

State	Nursing Homes			Personal Care			Total Nursing Home/Personal Care			% of MR Residents in Nur./Pers. Car
	Total Homes	Residents with MR	Res. w/MR per Home	Total Homes	Residents with MR	Res. w/MR per Home	Total Homes	Residents with MR	Res. w/MR per Home	
ALABAMA	96	687	7.16	6	17	2.83	102	704	6.90	26.3%
ALASKA	4	23	5.75	0	0	.00	4	23	5.75	6.5%
ARIZONA	23	45	1.96	24	120	5.00	47	165	3.51	6.9%
ARKANSAS	145	878	6.06	5	20	4.00	150	898	5.99	31.8%
CALIFORNIA	279	1,546	5.54	258	643	2.49	537	2189	4.08	7.0%
COLORADO	76	365	4.80	17	40	2.35	93	405	4.35	12.1%
CONNECTICUT	111	624	5.62	31	116	3.74	142	740	5.21	13.3%
DELAWARE	9	32	3.56	0	0	.00	9	32	3.56	4.5%
D.C.	4	69	17.25	0	0	.00	4	69	17.25	6.5%
FLORIDA	144	549	3.81	102	340	3.33	246	889	3.61	9.8%
GEORGIA	183	1,174	6.42	48	95	1.98	231	1269	5.49	26.8%
HAWAII	18	43	2.39	25	35	1.40	43	78	1.81	8.5%
IDAHO	20	83	4.15	9	37	4.11	29	120	4.14	8.5%
ILLINOIS	303	2,668	8.81	17	81	4.76	320	2749	8.59	17.0%
INDIANA	272	1,911	7.03	5	65	13.00	277	1976	7.13	26.8%
IOWA	181	845	4.67	23	206	8.96	204	1051	5.15	23.9%
KANSAS	88	243	2.76	2	4	2.00	90	247	2.74	6.2%
KENTUCKY	142	694	4.89	87	568	6.53	229	1262	5.51	43.7%
LOUISIANA	97	460	4.74	0	0	.00	97	460	4.74	7.5%
MAINE	72	228	3.17	44	85	1.93	116	313	2.70	14.3%
MARYLAND	75	323	4.31	3	5	1.67	78	328	4.21	7.3%
MASSACHUSETTS	299	1,400	4.68	45	198	4.40	344	1598	4.65	18.2%
MICHIGAN	262	842	3.21	500	1,086	2.17	762	1928	2.53	19.7%
MINNESOTA	163	871	5.34	11	39	3.55	174	910	5.23	9.4%
MISSISSIPPI	63	237	3.76	1	1	1.00	64	238	3.72	8.9%
MISSOURI	219	1,050	4.79	50	151	3.02	269	1201	4.46	16.8%
MONTANA	25	131	5.24	0	0	.00	25	131	5.24	10.1%
NEBRASKA	65	217	3.34	14	44	3.14	79	261	3.30	10.8%
NEVADA	14	52	3.71	6	14	2.33	20	66	3.30	13.2%
NEW HAMPSHIRE	20	144	7.20	16	40	2.50	36	184	5.11	14.1%
NEW JERSEY	95	303	3.19	87	382	4.39	182	685	3.76	7.5%
NEW MEXICO	19	78	4.11	17	40	2.35	36	118	3.28	7.8%
NEW YORK	222	1,544	6.95	129	556	4.31	351	2100	5.98	7.1%
NORTH CAROLINA	140	583	4.16	288	1,437	4.99	428	2020	4.72	31.0%
NORTH DAKOTA	48	253	5.27	9	43	4.78	57	296	5.19	17.3%
OHIO	225	1,633	7.26	20	130	6.50	245	1763	7.20	13.5%
OKLAHOMA	189	942	4.98	17	67	3.94	206	1009	4.90	20.8%
OREGON	69	325	4.71	18	79	4.39	87	404	4.64	11.4%
PENNSYLVANIA	181	1,050	5.80	209	802	3.84	390	1852	4.75	11.1%
RHODE ISLAND	40	173	4.33	3	22	7.33	43	195	4.53	14.3%
SOUTH CAROLINA	65	300	4.62	44	173	3.93	109	473	4.34	10.9%
SOUTH DAKOTA	43	117	2.72	4	8	2.00	47	125	2.66	7.4%
TENNESSEE	105	527	5.02	11	24	2.18	116	551	4.75	12.7%
TEXAS	301	1,099	3.65	12	32	2.67	313	1131	3.61	8.1%
UTAH	31	129	4.16	0	0	.00	31	129	4.16	7.1%
VERMONT	16	33	2.06	25	53	2.12	41	86	2.10	13.0%
VIRGINIA	99	531	5.36	91	480	5.27	190	1011	5.32	20.9%
WASHINGTON	130	867	6.67	26	159	6.12	156	1026	6.58	15.6%
WEST VIRGINIA	57	267	4.68	14	52	3.71	71	319	4.49	18.7%
WISCONSIN	148	1,695	11.45	19	39	2.05	167	1734	10.38	18.3%
WYOMING	7	17	2.43	0	0	.00	7	17	2.43	2.7%
U.S. Total	5,702	30,900	5.42	341	8,628	25.30	6043	39528	6.54	13.4%

The 1986 ILTCP findings appear to be quite comparable in indicating that the mentally retarded population made up 2.5% of the 1,533,253 residents of nursing and personal care homes. Although the ILTCP data are census in nature and are based on direct reporting of facility respondents, there are certain cautions that should be exercised. First, the distinction between mental retardation facilities and nursing/personal care facilities is not always perfectly clear. The distinctions become most clouded among the "personal care" facilities, which may be licensed or contracted to serve more than one population of persons with disabilities. Second, distinctions between mental retardation and cognitive impairments with onset outside the developmental period are not always clear among persons who operate nursing/personal care homes. On the other hand similarities between the ILTCP statistics and the estimates of persons reported to have a primarily medical diagnosis of mental retardation in the National Nursing Home Survey certainly seem to support a level of reliability.

Age and Gender

Table 13 presents population estimates from the 1977 and 1985 NNHS for persons with a primary diagnosis of mental retardation in nursing homes by age and gender. It shows an estimated 43,755 persons with mental retardation in nursing homes in 1977 and 40,539 in 1985. These estimates are not statistically different, with each of the estimates having a 95% confidence interval of approximately $\pm$ 4,000 residents with mental retardation. Similarly, differences in the estimated distributions of residents with mental retardation by age are not statistically different for any age group. In both 1977 and 1985 it was estimated that over half the mentally retarded residents of nursing homes were 55 years or older (55% and 56%, respectively). In both years it was estimated that 32% of residents with mental retardation were 65 years or older. These statistics compare with 13.2% of persons with mental retardation in mental retardation facilities being 55 or older and 5.5% being 65 or older (see Part II) (Scheerenberger, 1988). Population estimates of persons with mental retardation below the age of 65 in nursing homes were 29,797 for 1977 and 27,592 for 1985. Clearly, then, there are substantial age differences between persons with mental retardation in nursing homes and those in mental retardation facilities. But far more dramatic differences are evident between residents who are

Table 13

Estimated Number of Persons with Mental Retardation in Nursing and Personal Care Homes by Age

	1977-Residents with Mental Retardation		1985-Residents with Mental Retardation						1985-All Nursing Home Residents	
			Nursing Homes		Personal Care		All Homes			
	Est.N	%	Est.N	%	Est.N	%	Est.N	%	Est.N	%
AGE										
0-39	7,508	17.2	6,475	22.1	1,003	9.0	7,478	18.4	32.141	2.2
40-54	12,333	28.2	6,607	22.5	3,767	33.7	10,374	25.6	48,768	3.3
55-64	9,956	22.8	6,665	22.7	3,075	27.5	9,740	24.0	91,819	6.2
65+	13,958	31.9	9,606	32.7	3,340	29.9	12,946	31.9	1,318,672	88.4
GENDER										
Male	20,259	46.3	13,057	44.5	5,587	50.0	18,644	46.0	423,558	28.4
Female	23,496	53.7	16,296	55.5	5,598	50.0	21,894	54.0	1,067,842	71.6
EST. TOTAL	43,755		29,353		11,185		40,539		1,491,400	

mentally retarded and the general nursing home population. The latter is estimated to be 94.5% over 55 years and 88.4% over 65 years.

The percentage of females with mental retardation in the weighted sample was found to be higher than the proportion of males in 1977 and 1985 (54% to 46% in both years). The only statistically significant difference in the gender distribution between the 1977 and 1985 National Nursing Home Surveys came in the older than 65 years age group. In that group the proportion nursing home residents with mental retardation who were female increased from 56% to 62.5%. Despite the high proportion of females among the nursing home residents with mental retardation of 65 years and older, male representation within the elderly population with mental retardation was actually considerably higher than the estimated 28% males in the total nursing home population in 1977 and 1985. The 1985 NNHS indicated that very few nursing home residents with a primary diagnosis of mental retardation had ever been married (4%). No statistically significant differences were evident between the findings of the 1977 and that 1985 surveys.

Therapeutic Services Received

Table 14 shows the estimated percentage of nursing home residents who received selected therapeutic services in the month prior to the NNHS interviews in 1977 and 1985. Because need for these services may be associated with residents' age, this table subdivides three age categories into 54 years or younger, 55-64 years and 65 years and older. In general data from both 1977 and 1985 show relatively little use of basic therapeutic services by persons with mental retardation in nursing homes. Ten percent or fewer residents received physical therapy, occupational therapy, speech and language therapy, or psychological psychiatric evaluations or treatment over a one month period. Recreational therapy was the most frequently received service among both 1977 and 1985 sample members, with a substantially and statistically significantly smaller percentage receiving recreation therapy in 1985 than in 1977. Although the questions regarding "recreation therapy" were not different in the two surveys, it is possible that, with the growth of recreation therapy as a specialized profession, the interpretation of what constitutes recreation therapy from licensed, registered or professional trained

Table 14

Estimated Percentage of Nursing Home Residents with Mental Retardation

Receiving Selected Therapeutic Services[1] in the Previous Month

Therapy	1977				1985			
	≤ 54	55-64	≥ 65	Total	≤ 54	55-64	≥ 65	Total
Physical Therapy	10.6	8.5	6.6	8.9	10.6	3.0	2.2	6.1
Occupational Therapy	13.9	6.1	8.8	10.4	12.1	3.4	5.1	7.7
Recreational Therapy	35.0	19.7	28.8	28.1	18.3	6.2	12.3	13.5*
Speech & Hearing Therapy	.6	1.5	2.2	1.3	11.3	0.0	2.2	5.7
Psychological or Psychiatric Evaluation or Treatment	7.9	0.0	2.2	4.2	19.0	2.0	4.2	10.2

[1]Services provided to residents inside or outside the facility by licensed, registered, or professionally trained therapists.
*p < .05

therapists changed between 1977 and 1985. It is also possible that there was a substantial reduction in recreation therapy services for mentally retarded residents of nursing homes between 1977 and 1985. In either case the 1985 NNHS estimated that only 13.5% of residents received recreation therapy over a one-month period.

Limitations in Mobility, Sensory and Daily Living Functioning

Table 15 summarizes the percentages of nursing home residents with mental retardation estimated to have limitations in mobility, sensory impairments and/or daily living limitations in 1977 and 1985. No statistically significant shifts in the number of persons with these limitations were noted between the two surveys, with the exception of the number of persons said to need assistance with eating. About 17% in the two surveys were estimated to have visual impairments. Hearing impairments were estimated to be present in 7.4% and 8.4% of the nursing home population with mental retardation in 1977 and 1985 respectively. In both surveys about 20% of residents with mental retardation (18% and 22% respectively) were reported to need the assistance of other persons or special equipment to move from place to place. The 1985 estimate of 22% of nursing residents with mental retardation requiring assistance of equipment or other persons for mobility was the same as for persons with mental retardation in mental retardation facilities in the 1987 National Medical Expenditure Survey (also 22%).

Similar statistics were reported in 1977 and 1985 with respect to the number of persons with mental retardation requiring *any* assistance with bathing (about 80% in both surveys) and dressing (about 60% in both surveys). A significantly higher proportion of residents with mental retardation were reported to require some form of assistance with eating in 1985 than was reported in 1977 (35% versus 23%). Statistics from the 1987 National Medical Expenditure Survey estimated that among residents of all mental retardation facilities, 60% needed help with bathing, 53% needed some assistance with dressing, and 22% needed some assistance in eating. The same estimates for ICF-MR certified facility populations were 72%, 64%, and 30%, respectively. It appears, therefore, that persons with mental retardation in nursing homes are generally similar to those in ICFs-MR. However, one must always be

Table 15
Percentage of Nursing Home Residents with Mental Retardation
with Limitations in Mobility, Sensory Functioning and Selected Activities of Daily Living

	1977			1985		
	≤ 64 (N=29,797)	≥ 65 (N=13,958)	Total (N=43,755)	≤ 64 (N=26,592)	≥ 65 (N=12,946)	Total (N=40,539)
Limitations						
Mobility Impairment[1]	20.4	12.6	17.9	21.4	23.1	21.9
Visual Impairment	14.5	18.5	16.5	16.1	20.2	17.5
Partial[2]	11.1	10.8	11.0	9.9	4.5	8.2
Severe[3]	1.7	4.7	2.7	2.3	13.6	5.9
Blind[4]	1.7	1.1	1.5	3.9	2.1	3.4
Unknown Extent	1.0	1.9	1.3	0.0	0.0	0.0
Hearing Impairment	6.5	8.3	7.4	3.0	20.8	9.3
Partial[5]	6.5	5.8	6.3	2.8	20.3	8.4
Severe[6]	0.0	1.3	0.4	0.2	0.4	0.2
Deaf[7]	0.0	1.2	0.7	0.0	2.1	0.7
Requires Assistance with:						
Bathing[8]	78.9	84.9	80.8	77.0	83.5	79.1
Dressing[8]	60.1	51.8	57.5	62.0	67.2	63.6
Eating[8]	23.3	22.4	23.0	36.8	30.9	34.9*
Toileting Problems						
Daily Problem[9]	25.7	21.4	24.3	24.2	28.3	25.5
Several Times/Week	2.6	1.0	2.1	1.8	6.8	3.4
Once/Week	0.7	1.4	0.9	2.9	3.1	3.0
< 1/Week or unknown frequency	3.0	2.8	2.9	3.8	4.2	3.9

[1]Requires assistance of another individual or of special equipment (including wheelchair in moving from place to place).
[2]Cannot read newspaper print but can watch TV at 8-12 feet.
[3]Cannot watch TV at 8-12 feet, but recognizes familiar people at 2-3 feet.
[4]Less usable vision than severe visual impairment.
[5]Can hear most of the things a person says.
[6]Can only hear a few words a person says or loud noises.
[7]Less auditory acuity than severe hearing impairment.
[8]Respondent asked if subject ever requires any assistance.
[9]Includes ostomy, catheter, or other device.
*$p < .05$

cautious to recognize that definitions of whether assistance is needed may reflect institutional orientations and philosophies as well as the limitations of the individual residents.

Toileting problems of residents were reported to be essentially the same in both 1977 and 1985. In both years an estimated one-quarter of nursing home residents with mental retardation either had a bladder control problem involving at least a daily control problem or had an ostomy, catheter, or other device. In both years an estimated two thirds of nursing home residents had no significant bladder control problems (incidents less than weekly). This appears generally equivalent to the 68% of persons with mental retardation in mental retardation facilities who were reported to have "no difficulty" in using the toilet without assistance.

Facility Certification

The 1985 NNHS estimated that about three-quarters (73%) of persons with mental retardation in nursing facilities reside in facilities which are Medicaid certified as Intermediate Care Facilities (ICF) and/or Skilled Nursing Facilities (SNF). This compares with about 88% of all nursing home "beds" with Medicaid certification. The estimate from the 1985 National Nursing Home Survey of 29,200 ICF and SNF residents with mental retardation is quite similar to 28,600 persons with mental retardation reported to be in ICF and SNF certified nursing homes in the Inventory of Long-Term Care Places.

Despite considerable attention to the question of appropriateness of nursing homes for the long-term care of persons with mental retardation, their use changed very little in the years between 1977 and 1985. In 1977 residents with mental retardation were estimated to number 43,800; in 1985, 40,500. As in 1977 nursing homes remained a significant source of long-term care for persons with mental retardation, housing an estimated 14% of the nearly 300,000 persons with mental retardation living in licensed supervised residential settings (i.e., mental retardation and nursing facilities combined). Between 1977 and 1985, state institution populations decreased from 150,000 to about 103,000, while nursing home populations of persons with mental retardation changed relatively little.

Perhaps the most significant recurring findings of the National Nursing Home Surveys have regarded the relatively low prevalence of substantial physical and sensory limitations of residents with

mental retardation, the limited involvement in therapeutic services, and the similarities in reported "need for assistance" with basic activities of daily living between residents of nursing homes and ICFs-MR. These statistics suggest that nursing homes have changed very little in the past decade in response to the important questions being asked about their general appropriateness or special role in responding to the needs of persons with mental retardation. They would appear to provide considerable support for the reviews required in P.L. 100-203 for persons with mental retardation and related conditions. Based on medical needs and on physical/sensory limitations estimated in the National Nursing Home Survey it would seem unlikely that such reviews would find a substantial proportion of the persons with mental retardation and related conditions in nursing homes more appropriately served in nursing facilities than mental retardation facilities. Still, it remains to be seen what impact this law will have on nursing home placements, especially since individuals who have been residing in a nursing facility for 30 or more months (an estimated 67.7% of all nursing home residents with mental retardation in the 1985 NNHS) will be given the choice of remaining in their present facility. The law also requires, however, that those who remain must be provided a program of active treatment.

Appropriateness of nursing home placements. The 1985 National Nursing Home Survey and 1986 Inventory of Long-Term Care Places were consistent in indicating that nationwide about 40,000 persons with mental retardation are residing in nursing and personal care homes, and that about 29,000 of those persons are residing in SNF and ICF facilities. A recent survey of the "Alternative Disposition Plans" for nursing home residents with MR/RC (NASMRPD, 1989b) estimated from the reports of 45 states that there were 44,910 residents with MR/RC in nursing homes nationwide. In contrast to general consistency in estimates of the number of people with MR/RC in nursing homes, ILTCP indicated great diversity among the various states in the extent to which nursing homes are used to house persons with mental retardation. The ten case study states illustrated similar diversity among states in nursing home resident population.

The majority of the ten case study states reported that they had placed individuals with mental retardation in nursing homes relatively sparingly, or at least had never instituted a concerted policy to

use nursing homes as a primary placement option. Indiana, on the other hand, has used nursing homes extensively as part of its residential care system. Although it is no longer the state's policy or practice to place persons with mental retardation in nursing homes, many current residents have been identified by the HCFA Regional Office (Region V) as being placed inappropriately, and the state assumes that many if not most of the current estimated 2,000 nursing home residents with mental retardation will need to be transferred. Texas also has a large population of nursing home residents suspected to have mental retardation or other developmental disabilities (reported by the State in its Alternate Disposition Plan to number up to 3528), but it began an initiative in 1982 to transfer some nursing home residents found to be inappropriately placed and to develop a more extensive pre-screening activity. California has about 2,000 residents with mental retardation in state institutions with SNF certification and anticipates recertification of those facilities as ICF-MR, as well as the need to transfer 350-400 additional private nursing home residents with mental retardation and related conditions.

Other case study states report significant, but more limited, populations of persons with mental retardation and related conditions in nursing homes. But more importantly states report efforts to ensure reduction of inappropriate nursing home placements. Several states note that without mandatory pre-screening for all nursing home placements, families have continued to negotiate placements directly with nursing home operators, especially in states where many nursing home beds are available. This practice is exacerbated in areas where more appropriate placements within the mental retardation/developmental disabilities systems are not available. To respond to tendencies for persons to seek nursing home placements, many states have improved pre-screening activities with respect to appropriateness.

Other efforts have been instituted to discourage inappropriate nursing home placements, such as improved outreach regarding community service availability. Some states also have attempted to improve involvement of nursing home residents with mental retardation with the community-based service system. For example, case management has been provided by the local MR/DD authorities to nursing home residents in Colorado since 1983, and about half of the residents with mental retardation

and related conditions who live in nursing homes are participating in off-site community MR/DD day programs.

Many states have used nursing homes relatively sparingly as a residential care setting for individuals with mental retardation, with most nursing home placements limited to individuals in need of 24-hour nursing care and/or persons who are elderly. Individuals with other developmental disabilities may have been more likely to be placed in nursing homes; however, in many states placements of these individuals are not coordinated by the same agency that oversees the residential care of people with mental retardation. Several states which had previously placed large numbers of non-elderly individuals and those with less significant medical needs have taken steps to reduce the inappropriate utilization of nursing homes for such individuals, either upon the initiative of state government or as required by the Health Care Financing Administration.

The relative strength of the nursing home industry appears to be a factor in the extensiveness of nursing home utilization for individuals with mental retardation. For example, in Indiana, the nursing home interests were able to persuade the legislature to permit conversion of existing SNFs and ICFs to ICFs-MR, rather than requiring that people found by HCFA to be inappropriately placed in nursing homes be transferred to other residential care settings. Lack of control over nursing home placements, in particular those arranged directly between family members and nursing home operators, has also been a problem in some states. This is currently being in addressed by Florida and other states by new laws or regulations requiring approval by the state MR/DD agency for nursing home placements of individuals with mental retardation. However, states appear overwhelmingly committed to respond to the need to find alternative placements for nursing home residents with the development of community-based alternatives. For example, there were no indications of a tendency within the MR/DD agencies of the case study states to support responding to the major problems they face under P.L. 100-203 through the expediencies of recertification of nursing homes or units of them as ICF-MR.

In sum, the general trend among the states, beginning prior to the enactment of the federal nursing home reform legislation in OBRA 1987 (P.L. 100-203), has been to consider nursing homes an

inappropriate placement for almost all individuals with mental retardation and other developmental disabilities unless they require skilled nursing care; many states are also developing alternatives for medically fragile individuals (e.g., the new ICF-DD-N program in California). At the same time, there is considerable uncertainty in many states as to the full implications of P.L. 100-203 in relation to the individuals currently placed in nursing homes, as discussed in the following section.

Since the enactment of P.L. 100-203, most states have taken steps to assess the current implication of the law on nursing homes for individuals with mental retardation and other developmental disabilities. Some states already have developed preliminary estimates of the number of individuals with mental retardation and other developmental disabilities who would most likely have to be moved from nursing homes to other residential care alternatives, i.e., those who have resided in the nursing home less than 30 months; are not elderly; and/or who do not require 24-hour nursing care. Among the case study states, by October 1988 all ten had prepared at least a preliminary estimate (such as a file review of Medicaid-funded nursing home residents by primary diagnosis) of the number of persons potentially needing new placements. These estimates, generally 30-40% of persons with MR/DD living in nursing homes, ranged from 230 (Minnesota) to about 2,400 (Indiana). Nine of the ten case study states reported they were in the process of a more detailed assessment. The tenth state, Indiana, had previously completed a detailed assessment of nursing home utilization for individuals with mental retardation and related conditions in conjunction with earlier federal reviews that found that nursing homes were being used inappropriately as placements for this population. Indiana's 1986 nursing home review identified 2,377 individuals with mental retardation and other developmental disabilities who were under the age of 65 and with no primary medical conditions.

Issues and effects of P.L. 100-203. The issues of greatest concern to the states in the implementation of P.L. 100-203 revolve around the requirement that residents with mental retardation receive active treatment. Specific concerns include questions as to who can provide the active treatment, in particular whether it can be delivered on-site by nursing home personnel. The resolution

of these questions will have significant impact on the requirements states must meet in implementation and therefore the costs of implementation.

Many states with mental retardation (as opposed to MR/DD or developmental disability) agencies are facing some coordination issues in relation to the review and alternative placement of individuals with developmental disabilities other than mental retardation. Responsibility for these individuals is unclear in some states, or may be divided among multiple agencies. Although the mental retardation agency may have the lead on the overall implementation of P.L. 100-203, it may have had no role in the nursing home placement of individuals with developmental disabilities other than mental retardation, nor have any involvement in whatever community-based alternatives might be available to them. Indeed, in some states historical distinctions between mental retardation (served by the mental retardation agency) and other conditions now considered developmental disabilities may have contributed substantially to the problem of inappropriate nursing home placement, and are expected to create ambiguities with respect to what services are appropriate and which service systems would best meet the needs of certain individuals.

Regardless of a state's MR versus MR/DD orientation, program agencies in many states are also projecting increased involvement in screening future nursing home placements, to avoid inappropriate utilization; such screening is an additional requirement of P.L. 100-203. It is common in most states for families to be able to arrange for nursing home placements for their relative with mental retardation and related conditions outside the purview of the MR/DD service system. States are expected to develop a variety of ways to control families' access to nursing home placements over the next few years.

Most states are unsure of the likely effects of implementation of P.L. 100-203 on their residential service systems. Most of the case study states, for example, are waiting for the analysis of the more detailed assessments underway in order to develop plans based on specific estimates of the number of individuals who will require alternative arrangements. States which have developed preliminary plans generally project the use of small ICF-MR facilities as an alternative, or, if not expanding small ICF-MR facility utilization, use of the HCBS waiver. At least one of the case study states (Florida) is planning

to develop a separate waiver target to clients moved from nursing home placements. Some states plan to at least consider the conversion of SNF/ICF certified units to ICF-MR; however, other states are opposed to this approach.

Some states are relatively unconcerned about the potential effects of OBRA implementation on the residential care system, either because they have already taken steps to address the nursing home placements issues (e.g., Indiana) or because the number of nursing home placements--especially recent and nonelderly placements--is small (e.g., Mississippi). Other states, however, are very concerned about the potential impact on their overall MR/DD residential care system. Among the case study states, for example, Connecticut feels that the diversion/alternate placement of nursing home residents will consume all the resources for community-based services development and community residential facility openings, resulting in lack of services for community consumers. For example, among the case study states Texas projects up to $90 million in additional costs if the state were required to relocate the present MR/DD nursing home residents.

PART VI: OTHER MEDICAID OPTIONS

Background

Medicaid law distinguishes two types of services. One type, "mandatory services," is required to be provided to categorically eligible people (i.e., aged, blind, disabled, member of families with "dependent children," and other groups of children and pregnant women who are in poverty as defined by S.S.I. or A.F.D.C. eligibility) by all states participating in Medicaid. Mandatory services include physician services, inpatient and outpatient hospital services, early and periodic screening, diagnosis and treatment of children, laboratory and X-ray services, skilled nursing facility (SNF) services for adults, and home health services for persons who would otherwise be entitled to SNF services. States also have the option of providing Medicaid reimbursement for a broad range of additional services to Medicaid-eligible individuals, in addition to the mandatory services. (ICF-MR and ICF-general are among the 32 optional services states can choose to offer.) Certain basic health-related optional services are provided by states to their Medicaid eligible citizens universally or nearly so (e.g., optometrist-eyeglasses services, prescription drugs, clinic services, emergency hospital services, dental services, prosthetic devices), albeit with varying levels of coverage as determined by the individual states. Many persons with mental retardation and related conditions living outside of Medicaid certified institutions, as well as many residents of certified facilities, benefit directly from a range of mandatory and state-option basic health services in almost all states by virtue of their usual eligibility for Medicaid (i.e., being people who are both disabled and low income). These Medicaid services contribute in important ways to the well-being of persons with mental retardation and related conditions.

Other Options for Persons with Mental Retardation

In addition to the general benefits persons with mental retardation and related conditions derive from basic Medicaid health service options, there is a range of Medicaid options of specific interest to state MR/DD and Medicaid agencies for their ability to respond to the specific needs of persons with developmental disabilities. Several optional services within the Medicaid program have been identified by states as resources for assisting individuals with mental retardation and other developmental

disabilities and their families, in particular case management, personal care, habilitation/rehabilitation services, and optional extension of categorical eligibility to non-institutionalized children with disabilities.

Based on the state surveys, many states are currently including these options or are considering them for future state Medicaid plans, as follows (*indicates a case study state):

- Case Management (AL, CA,* CO,* FL,* GA, HI, IL, ME, MD, MI, MS,* NE, OR,* NE, PA, SC, TX,* UT, VT, WV, VT)
- Personal Care (AR, LA, ME, MI, MT, NY,* WV, WI)
- Habilitation Services (AR, GA, IL, ME, TX,* WV)
- Eligibility for Disabled Children (AR, MI, MN*)

The Medicaid optional service of greatest interest to states in relation to their MR/DD service system is case management. Targeted case management services were added as a Medicaid option in 1986 (P.L.99-272). Section 1915(g) of the Social Security Act, as currently amended, permits states to claim Medicaid reimbursement for case management provided to targeted groups of Medicaid-eligible people in order to "assist individuals . . . in gaining access to needed medical, social, educational and other services." This specific authorization makes the option considerably more attractive in that ambiguities around its qualifications for reimbursement have been removed. There is some interest in the financing of other services through the Medicaid program as part of state MR/DD service systems, such as rehabilitation services, clinic services, and the home care option permitted by TEFRA. These services are not expected to affect significantly the projected utilization of residential care services, except to the extent that the availability of community-based services permits expanded use of options to institutional care or permits more individuals to receive home-based services that may serve at least to defer requests for residential care outside the home. In general, however, states seem to be taking a cautious approach to the expansion of Medicaid optional services, associated in particular with concerns that states not increase their obligation significantly for the non-federal Medicaid match.

Case management. In all 22 states reported they were using or were presently considering the use of the case management option. Among the case study states six of the ten (California, Colorado,

Florida, Mississippi, Oregon, and Texas) either currently include case management as an optional service or plan to add it to their state Medicaid program. Mississippi already is providing Medicaid-financed case management to individuals with mental retardation as a discrete optional service. Oregon includes case management within its Medicaid administration plan, an optional approach used by several states which does not require the designation of targeted case management as an optional service. Three additional states (California, Colorado and Florida) plan to add case management to their state Medicaid program in the near future. California is currently appealing HCFA's initial refusal to approve their addition of this option. Of course, case management is a central and widely used part of the mental retardation services system in virtually all states, regardless of its status as a Medicaid optional service. As such it is used to promote appropriate utilization of the ICF-MR program and alternative residential care options as part of the initial assessment and screening process and throughout the period of residential service utilization. It is also critical to the planning, authorizing and coordination of basic nonresidential services and supports. Case management may reduce the demand for residential care in some instances, for example, by arranging for home-based or community-based services that permit the individual to remain in the family setting. Case management may further reduce or delay demands for long-term care because of its basic role in the authorization, delivery and monitoring of services and because case management has considerable potential to promote an individualized approach to services. Continued growth in the use of the targeted case management option is likely to occur in the absence of particularly difficult experiences by the states first exploring this relatively new option or major reform of the whole Medicaid program for persons with mental retardation and related conditions.

Personal care. Personal care services can be reimbursed by Medicaid if prescribed by a physician in a Medicaid individual's plan of care, supervised by a registered nurse and provided in the individual's home by someone other than a family member. Only 25 states utilize this as a separate Medicaid option, although some personal care services may be covered under other service categories, such as home health care, in some states. In most states offering personal care in their Medicaid

program the service is generic, that is, it is provided without differentiation for specific categories of Medicaid-eligible populations. For example, one of the largest personal care programs is found in Texas, with total Medicaid expenditures of nearly 90 million dollars and nearly 29,000 total recipients in FY 1987. Persons with mental retardation are eligible for the program, but on the same basis as other citizens, that is, because of specific medical needs. (Presumably most states utilizing this option would include within its generic application people with medical needs who happened to be mentally retarded.) Nine state MR/DD agencies did report specific uses for persons with mental retardation and related conditions. Frequently states that use personal care in a focused way for persons with developmental disabilities serve persons on the "fringes" of the population of persons with mental retardation and related conditions, often people with severe physical disabilities. But New York reports personal care to be an important option for persons with mental retardation and other developmental disabilities and one for which need is considerably greater than supply. Michigan is another state that has considerable successful experience in using the personal care option for persons with developmental disabilities.

Day habilitation. Medicaid reimbursement for daytime developmental services is available for persons in ICF-MR facilities for both facility provided and off-campus "active treatment" programs delivered by another provider through a service contract. Many states also provide daytime developmental services as part of their Medicaid waiver programs. In addition, a few states attempt to gather Medicaid reimbursement for community-based day programs under the Medicaid optional "Clinic Services" or the "Diagnostic, Screening, Preventive and Rehabilitative Services" in their state plans. Because of these various ways of funding day habilitation services, there is often confusion about the extent to which states fund habilitation under Medicaid options other than the ICF-MR and Medicaid waiver programs.

The appropriateness of the "Clinic Services" and "Rehabilitation Services" options for daytime developmental services has been a point of contention between HCFA and various individual states throughout much of the 1980s. The Medicaid waiver provided a clearly authorized alternative for funding habilitation services to which many states have turned in recent years. The problem for states is, of

course, that most find themselves significantly limited in the number of individuals living at home or in noncertified community-based residential settings that they can serve through the Medicaid waiver, because of its cost-neutrality requirements. States therefore continue to show interest in the Medicaid options as a means of funding day habilitation services. Among states utilizing these options is Georgia, which currently covers various therapeutic, rehabilitative counseling, diagnostic assessments, and case management services under outpatient clinics in its Medicaid state plan, as do Arkansas, Maine and West Virginia. Texas is currently submitting a State Plan amendment to provide day habilitation as well as other services under the rehabilitation services option for persons with MR/RC and with mental illness. Illinois recently (1987) began a program to fund day habilitation programs for many individuals with mental retardation living in nursing homes. This is a case where the waiver cannot be used because the people still live in Medicaid facilities and "active treatment" services are not otherwise authorized for reimbursement because the facilities are not ICFs-MR.

Eligibility for disabled children (TEFRA). The 1987 Tax Equity and Fiscal Responsibility Act (TEFRA) gave states the option of providing Medicaid services to disabled children and youth living at home. Although not an optional service per se, it is an important state option with respect to Medicaid coverage of services for children and youth with significant impairments, including mental retardation and related conditions. It allows states to extend Medicaid categorical eligibility to children and youth who would meet the level of care requirement for institutionalization and would be eligible for Medicaid if they lived in an institution. In other words, children with disabilities do not have to be placed in a hospital or other medical care facility in order to be eligible for Medicaid, even if the family does not meet income and resource standards. Services that can be offered under this option can only be those generally available under the state plan, that is, the state cannot offer specific services to this group of children and youth. Further, if a state uses this option, the available services must be made available to all eligible children and youth, a provision which may make it less attractive than the use of the "model" waiver for such children, which states are permitted to limit in very significant ways, including specific characteristics of people covered, current situations of people covered, total number

of people covered (to a maximum of 200), and the specific services to be covered. While 22 states report use of the TEFRA option, only three states reported current use of the TEFRA option specifically for children with MR/RC (Arkansas, Michigan, and Minnesota). As a new option within the states, it was difficult to estimate its likely eventual impact. Minnesota's respondent did note that a disappointingly small number of people had taken advantage of the option to date.

Factors affecting use of options. State decisions about the use of Medicaid optional services to finance services to individuals with mental retardation and other developmental disabilities reflect consideration of a mix of financial and programmatic issues, and a good deal of uncertainty. Among some of the case study states, the positive aspects of the state options include 1) their providing FFP to improve and expand individualized community-based services, particularly to persons living at home, and 2) their potential for contributing to the reduction of need for residential care services, although there was little certainty about this as a sure outcome. On the other hand, several states are concerned about the overall increased state costs, despite the increased FFP. This is more a concern where programs are new (e.g., TEFRA), as opposed to existing services for which states have much history of providing them (e.g., case management, day habilitation), and where the issue is largely one of financing. But even among existing services there was concern that the federal requirements associated with some of the optional services could increase their cost to a point beyond what would be offset by the federal cost-share. State MR/DD agencies also note that optional services under Medicaid are often more medically oriented than is appropriate for the vast majority of individuals with mental retardation and other developmental disabilities. For example, Oregon decided not to add the personal care option for this reason after reviewing the relevant requirements. A few states have noted past or current federal control and oversight of state activities as a factor which discourages them from using Medicaid optional services as part of their MR/DD service system. States were also concerned about the extent to which HCFA would accept the tailoring of optional state services in response to the specific needs of persons with developmental disabilities and/or the extent to which continued HCFA approval could be counted on once a program was initiated.

Effects of options on ICF-MR and other services. States tend to see the other Medicaid options as potential resources for funding elements of their community-based MR/DD service system. In general states comment that if these "other" Medicaid options have any effect on Medicaid long-term care utilization, they do so by delaying placements rather than permanently preventing them. If actually achieved, this has two important benefits for states. First, it effectively reduces the overall needed capacity of long-term care, by increasing the average age at which people enter residential care and therefore the total number of years they spend in it. Minnesota specifically noted that it expects eventually that the TEFRA home care option will have just this effect. It also helps states deal with the immediate pressures of unmet need. (People may not get what they want, but they can get something that helps.) This is especially true in situations where services to children with developmental disabilities and their families (including special education provided through the public school system) are proving extremely effective in reducing the use of out-of-home placements, but where adult services openings are not available when families find the time appropriate for out-of-home placement of their young adult relative (Minnesota, Oregon).

PART VII: SUMMARY AND CONCLUSIONS

Title XIX of the Social Security Act (Medicaid) provides most federal funding to support services for persons with mental retardation and related conditions (MR/RC). The Intermediate Care Facilities for the Mentally Retarded (ICF-MR) program is the largest of all Medicaid programs for persons with mental retardation and related conditions. Enacted in 1971, largely to assist in correcting the deplorable conditions then existing in public institutions, it has been the focus of considerable attention in recent years. A number of reasons can be cited for widespread interest in the program, including 1) the size of ICF-MR expenditures ($5.6 billion in Fiscal Year 1987); 2) the rate of growth in ICF-MR expenditures (from $1.1 billion in fiscal year 1977 to $5.6 in fiscal year 1987); 3) the growth in the total number of ICF-MR beneficiaries (from 106,166 on June 30, 1977 to 144,350 on June 30, 1987); 4) the high average cost per beneficiary (about $37,600 per person in FY 1987); and 5) its institutional orientation at a time when professional opinion, research findings and changing patterns of residential services delivery all strongly favor noninstitutional care (in FY 1987, 86% of ICF-MR expenditures went to facilities of 16 or more residents).

Today states are looking for ways to increase the involvement of the federal government in providing community-based services. There is widespread concern that the ICF-MR program, now nearly two decades old, is out of step with the prevailing standards for residential and related services for persons with mental retardation and related conditions. Much of the contemporary interest in the Medicaid Home and Community-Based Services (HCBS) waiver reflects the perception that it is a much more appropriate model of federal financial cooperation in providing the kinds of individualized, community-based services favored by most states. The HCBS waiver was authorized by Congress in 1981 to permit states to finance through Medicaid certain Home and Community-Based Services for persons with MR/RC who would otherwise face institutionalization. The waiver has responded to many of the specific criticisms of the ICF-MR program by supporting community-based alternatives to institutional care. However, because its initial purpose was to reduce overall long-term care costs, it

places significant limitations on the extent to which it can be used by states to expand opportunities for people with MR/RC to live in community settings.

Today virtually all states are moving steadily to increase community living opportunities and decrease institutional placements of their citizens with MR/RC. A wide range of statistics can be cited to show the rather dramatic changes in the kinds of housing provided to persons with mental retardation and related conditions. Perhaps most notable is that the service system for persons with MR/RC in most states serves more people living in community settings (homes with 15 or fewer people with disabilities) than in institutions. Community services have become the norm. This trend has been supported by a substantial and growing body of research showing significant benefits of community versus institutional living in important areas, including development of basic skills of daily living and involvement in culturally typical activities. With only a few exceptions, states demonstrate commitment to continuing deinstitutionalization along with expansion of community living opportunities for their citizens with MR/RC. Since 1967 there has been a continuing reduction in the use of large state institutions, from an average daily population of 194,650 in 1967 to 151,532 in 1977 to 94,696 in 1987. Over the past 10 years there has been a rapidly increasing number of people in facilities of 15 and fewer residents, from 40,433 in 1977 to 63,703 in 1982 to 118,570 in 1987.

Despite the major success of states in achieving the nearly universally held goals of institutional depopulation and community services development, states consistently note two broad problem areas. States consistently describe themselves as having insufficient resources to fully meet goals for developing community services, particularly as institutional expenditures continue to increase despite decreasing populations. States are also faced with extensive waiting lists for community residential care and other adult services while lacking resources to respond effectively to the magnitude of needs.

States clearly are in need of and seek expanded federal participation in providing community-based services. When Congress created the original Medicaid ICF-MR benefit it clearly intended to promote the prevailing state-of-the-art in service delivery. In the two decades that have followed the state-of-the-art has changed dramatically, and in its pursuit most states find the ICF-MR program to be

of diminishing value. The vast majority of states would welcome a renewed and updated commitment by the federal government to promoting the prevailing standards of service delivery.

Statistics support the perception that the ICF-MR option is decreasingly useful within the contemporary services system. For example, after rapid growth following enactment, the ICF-MR program in the past several years has hardly changed at all in the number of people served and is projected to decrease in persons served by June 1990. From June 30, 1977 to June 30, 1982, the number of ICF-MR facility residents grew from 106,166 to 140,684 (33%). In the subsequent 5 years, ICF-MR facility residents grew only another 3,666 persons (2.6%) to 144,350 on June 30, 1987. The number of ICF-MR residents actually decreased in a majority of states from 1982 to 1987. States project that between June 30, 1987 and June 30, 1990 ICF-MR populations will decline by about 3,400 residents (2.3%). But despite stable numbers of ICF-MR residents, ICF-MR expenditures have continued to increase rapidly. Total ICF-MR expenditures for fiscal year 1987 were $5.6 billion, compared with $3.6 billion in 1982. ICF-MR per beneficiary costs in fiscal year 1987 were about $37,600. This compares with $10,300 in 1977 and $25,600 in 1982.

Clearly the Medicaid program with the most widespread philosophical and programmatic attractiveness to states today is the Medicaid waiver. Since enactment in August 1982, the Medicaid Home and Community-Based Services (HCBS) waiver has become of significant and growing importance to state MR/DD service systems. States with HCBS authority and those in the process of applying for it cite its flexibility, its support of community-based residential options, and its availability for services that may obviate or delay institutionalization as its major strengths. Recent national trends in state utilization and observations by states regarding Medicaid Home and Community-Based Services support the general observations of state respondents regarding the program. For example, the number of states participating in the program is increasing. On June 30, 1988 a total of 40 states were providing Home and Community-Based Services to persons with mental retardation/developmental disabilities. In the four years following enactment, Medicaid HCBS waiver participation went from zero to over 20,000 persons served. Between June 30, 1985 and June 30, 1987 the total number of waiver service

recipients grew only 8% (to a total of 22,700), but the relatively low rate of growth was due primarily to a huge reduction of about 4,350 beneficiaries in Florida. Excluding Florida, total waiver recipients grew by 26% between June 30, 1985 and 1987. Statistics for FY 1988 show a large one year increase in both waiver beneficiaries and expenditures. Reported waiver recipients for FY 1988 increased to 29,450 from 22,700 in FY 1987 (29.7%). Expenditures increased to about $450 million (from $294 million) during the previous year.

One reason for the attractiveness of Medicaid waiver services is their very favorable cost comparison with ICF-MR services. Average annual HCBS costs in 1987 were about $13,200 for each recipient. Comparable costs for ICF-MR services in 1987 were $37,600 per recipient. But most commonly states see the strength of the HCBS waiver to states as its consonance with their policy objectives. In recent years states have focused the policy objectives primarily on areas of community and family living and on developing arrays of services that respond to individual characteristics and life circumstances. The flexibility of HCBS is virtually universally acknowledged by states as permitting them to pursue these goals with much needed federal financial participation in ways not possible under other Medicaid programs. The waiver has also helped states to demonstrate the potential of small, non-institutional residential options for people with the most severe disabilities, including challenging physical, health and behavioral conditions.

The primary limitation seen with the Medicaid HCBS waiver is the cost-neutrality requirement. States participating in the HCBS program, as well as those who do not, cite restrictions in waiver expenditures to savings in institutional expenditures as the program's major limitation in assisting them in providing the services needed by their citizens with MR/RC. This limitation has resulted in the restriction of available funding, in the number of persons allowed to benefit, and in many states in the characteristics of persons allowed to benefit. In a few states people with severe cognitive, physical and/or behavioral impairments are reported to have limited access to community services because of the limited funds available for Medicaid waiver services.

There will be continued evolution of long-term care systems toward a predominantly community orientation. By Fiscal Year 1987 the average daily population of state institutions had decreased to less than half the population of 20 years earlier, with only 37% of the June 30, 1987 residential populations housed in state institutions. By June 30, 1990 states project that 31% of their residential populations will be housed in state institutions. On June 30, 1987, 46.5% of all persons in residential settings for persons with mental retardation were living in small, community settings, and states project that by June 30, 1990, 53% will be in small community facilities. Even from among their nursing homes, which have had relatively stable populations of about 40,000 residents with mental retardation since 1977, states will be compelled under P.L. 100-203 to move thousands of individuals with MR/RC into mental retardation facilities. With important federal financial assistance through specialized waiver programs, most will enter community settings. Community services are no longer an alternative to institutional care, in most states they are the primary model of care. Findings of this study suggest urgency in the federal government's recognizing a future in which community care will be increasingly predominant by reforming Medicaid in ways that assist in responding to the serious problems facing states in delivering community services.

There are currently before Congress two major legislative proposals that are intended to respond to the problems now facing states; they are the Medicaid Home and Community Quality Services Act of 1989 (S. 384) and the Medicaid Community and Facility Habilitation Amendments of 1989 (H.R. 854). Both contain features that would be attractive to most states in responding to the problems presently affecting them. But both also contain features regarding which some states feel considerable ill-ease. In the concluding pages of this report, problems currently facing states are rearticulated with attention to how these two current Medicaid reform bills respond to them.

- *States need a form of financial participation from the federal government that is not determined by where one is placed.* The level of participation of the federal government in institutional programs through Medicaid is much greater in total funds and proportion of beneficiaries than community-based programs. While 88% of all residents of large institutions are in Medicaid-funded ICFs-MR, only about a quarter of community facility residents had Medicaid participation in their care from either the ICF-MR or Medicaid waiver program. The primary source of federal contribution to community living for persons with mental retardation remains SSI. But its federal contribution to community living for persons with mental retardation was about one-fifth the average daily ICF-MR

federal contribution in fiscal year 1987. States are reluctant to develop small facilities meeting the institutional ICF-MR standards simply to attain federal cost-sharing. They note preference for service decisions based on the principles of individualization, purchasing services rather than facilities, and maintaining flexibility in program options. But they observe that it is not fiscally possible to base policy strictly on such factors when large amounts of federal financial support lie in the balance. Both current Medicaid reform proposals would offer significant improvements in states' ability to obtain federal financial participation for services based on individual need rather than place of residence.

- *States need flexibility in the services they may provide under Medicaid.* States nearly universally view their experience with Medicaid Home and Community-Based Services as positive. Criticism of the program is largely limited to administrative issues related to its limitations on expenditures and its temporary approval provisions (3 years for new applications, 5 years for renewals). Most states are philosophically committed to providing services and supports based on individual needs. When presented with a specific legislative proposal providing broad flexibility in the range of services that could be offered under Medicaid (S. 384, the Medicaid Home and Community Quality Services Act of 1989), 38 of 51 state respondents in 1988 indicated agency support of the legislation as an alternative to present policy. The fact that 40 states are now providing Medicaid Home and Community-Based services under the "waiver" option despite financial limitations suggests that H.R. 854 would be highly attractive among states. Reservations exist among states with both pieces of legislation. Many states are concerned about limitations on FFP for larger facilities in S. 384. States have many reservations about the proposed "federalization" of standards and quality assurance for community-based services under H.R. 854. But despite these reservations both proposals represent reform that would assist the vast majority of states already committed to community service development.

- *The rates at which a few states are creating community living opportunities for their citizens suggests a possible desirability of proactive federal involvement.* A substantial body of research shows substantial and consistent benefits accrue to people with mental retardation when they move from large institutions to community facilities. In the Developmental Disabilities Assistance and Bill of Rights Amendments Act of 1987 Congress noted that "it is in the national interest to offer persons with developmental disabilities the opportunity, to the maximum extent feasible, to make decisions for themselves and to live in typical homes and communities where they can exercise their full rights as citizens." Very impressive progress is generally being made in this direction nationally and in most states. But in a number of states, this "national interest" is being poorly attended to. H.R. 854 contains no preferential incentives for community-based care, but it does attempt to simply "level the field" between Medicaid support of institutional and community services. As such H.R. 854 may be sufficient to encourage states to move in the direction ostensibly supported by Congress and clearly supported by prevailing professional standards. However in some states incentives to reduce institutional populations by reducing real dollar federal contributions for institutional care as proposed in S. 354 may more directly promote the national interest as defined by Congress. One problem with an effective nominal dollar cap on institutional expenditures is that it would reduce real dollar federal contributions for institutional care in a substantial number of states that are already decreasing institution populations, but are also simultaneously attempting to upgrade services in all or some of their institutional settings. It may be possible to develop compromise between the indifference of H.R. 854 to continued institutionalization of people with MR/RC and S. 384's likelihood of reducing federal funding needed to maintain or upgrade current services in large facilities in some states that are actively pursuing deinstitutionalization. For example, a modest compromise would be to allow a state's rate of depopulation of large facilities to serve as a credit to balance up to an equal amount of increased institutional expenditures. At rates of institutional depopulation incurred over the past 10 years, such a plan would add less than 5% to the costs of S. 384, while maintaining substantial limits on the potential increases in institutional expenditures under H.R. 854.

- *States need substantially increased sources of funding for community services to meet current and projected needs.* Most states are currently reporting substantial numbers of persons awaiting entry into their services system. They also note substantial difficulties in obtaining funding to cover the costs needed to sustain existing and needed community services for people leaving state institutions. Because of a shortage of funding states observe a wide range of problems including: insufficient number of programs are being developed, community facilities are inadequately compensated, community staff are considered underpaid with related problems of staff turnover, inadequately qualified staff, and insufficient funding for staff training. Both S. 384 and H.R. 854 would be sources of significantly increased funding for community services that would assist greatly with these problems. But both would, of course, require state funding to "leverage" the federal financial participation. A particularly difficult problem reported by states in increasing state resources to support community services has been their inability to reduce institution costs as populations have decreased. Between 1982 and 1987 state institution populations decreased by 19% while total expenditures increased by 12%. The inefficiencies of operating large institutions at far below capacity with fixed costs spread over fewer people clearly contribute significantly to the rapidly increasing costs of institutional care. Federal contributions of 50% to 80% of these increases may serve to defer economical decisions regarding consolidation and closing of inordinately inefficient and costly settings. S. 384 would require states to evaluate the efficiency of their institutional capacity in a much more serious way than H.R. 854. It would quite likely over time redirect considerable amounts of funding that otherwise would have gone to institutional services to community-based services. However, the important feature shared by both proposals is that open-ended federal cost-sharing would for the first time be made available under the same basic conditions that now prevail for institutional services. Most states report themselves to need these resources to realize the principles and service goals they have articulated for their citizens with MR/RC. The maintenance of effort provisions of S. 384 may be one important way of insuring that the new federal resources actually do create new opportunities for persons with MR/RC and not merely replace current state funds.

- *States need to respond to large numbers of persons awaiting community services.* States report large and growing numbers of persons awaiting services. A number of factors are identified as contributing to this problem. These include limited growth in total residential capacity in the past 10 years, an unprecedented proportion of the population in the young adult years (18-39) in which most persons enter residential care, increasing longevity of persons with mental retardation, and parental refusal of the unused capacity in institutions. Most states are not optimistic about improvements in this situation in the near future as a range of factors make it difficult for states to respond to the needs of those presently awaiting services. Among factors cited by states as contributing to this difficulty are limited funding for new facilities, inadequate funding to stimulate a provider market, and demands of court orders, laws and state policy focused primarily on bringing residents of mental retardation institutions and nursing homes to community settings. Despite the growing need, the only legislative proposal to date that would explicitly prohibit indefinite denial of comprehensive services to certain individuals (persons defined as severely handicapped) was a 1988 proposal by a working group on federal programs for persons with MR/RC within the U.S. Department of Health and Human Services. S. 384 would mandate that states participating in the Medicaid program provide a core set of "community and family support services" on a statewide basis. Mandated services would include individual and family support, specialized vocational services, case management and protective interventions. Other services could be offered on an optional basis. H.R. 854 would make all community habilitation and supportive services a state option. But both current legislative proposals would provide substantially increased opportunities for states to access federal funds in responding to the current unmet need for community-based services.

- *States acknowledge significant limitations in monitoring and directly contributing to quality of life in community facilities.* Minimal quality assurance and efforts to improve the quality of life of persons living in community settings is increasingly noted as a problem for states. Case management resources are frequently seen as too limited to establish caseloads permitting adequate involvement with clients to insure quality. Procedural monitoring activities are impaired by limited resources in an era of increasingly dispersed sites. Efforts to establish citizen monitoring by advocacy groups and a few state agencies, although increasing, remain in relatively early stages of development. After years of extremely limited federal oversight of community programs, ranging from relatively little among community ICFs-MR to none for waiver services and state-funded programs, there is substantial variation within and across states in the nature, amount and perceived effectiveness of quality assurance. One important factor in these differences have been the Medicaid matching rates for quality assurance as part of states' ICF-MR survey and certification and inspection of care activities, while Medicaid waiver and state funded programs depend nearly entirely on state funds for quality assurance. States also vary in their promotion of higher quality through training and technical assistance supports, and a number of states consider the limited qualifications of staff recruited and the inability to retain experienced staff as a major issue in providing quality services. Differentiating the relative need for more extensive resources for state monitoring and technical support of service providers as opposed to more stringent or detailed federal standards for community services could not be determined from this study, though states obviously prefer the former. S. 384 and H.R. 854 differ significantly in their response to this issue. S. 384 would require the individual states to develop a comprehensive quality assurance system which would include standards and methods for evaluating each type of service offered and outcome measures for recipients. The role of the federal government would be to insure such standards are in place and monitor state compliance with them. In contrast H.R. 854 would establish explicit federal standards for the whole range of community habilitation and support services authorized in the legislation. Based on their experience with Home and Community-Based Services most states would argue that the former approach is more appropriate to an individualized focus on service delivery. Extensively detailed ICF-MR standards are viewed as a major problem in delivering community residential services in small ICFs-MR. Such problems might likely be exacerbated in settings like foster homes and semi-independent living arrangements. Many states with well-developed community standards and quality assurance mechanisms would find federal standards aggravating and possibly detrimental to their systems. On the other hand, many states recognize that the current standards and quality assurance in community settings needs improvement, including improved funding for monitoring. Two issues arise with respect to the differing approaches of S. 384 and H.R. 854. First, will the benefit of a set of minimal federal standards for community services offset the cost of lost flexibility to meet specific individual needs? Second, will states with well-developed standards and quality assurance programs be adversely affected by federalized standards? States would obviously prefer the "trust" incorporated into S. 384, but not all have earned it. But consideration of the "federalization" approach as proposed in H.R. 854 should include consideration of provisions to grant waivers for performance to states that have already developed appropriate standards and effective monitoring practices for their community-based services for persons with mental retardation and related conditions.

APPENDIX A: BEHAVIORAL OUTCOMES ASSOCIATED WITH MOVEMENT FROM STATE INSTITUTIONS TO SMALL COMMUNITY LIVING ARRANGEMENTS

Table A-1

Experimental/Contrast Group Studies
Behavioral Outcomes Associated with Movement from State Institutions
to Small (15 or Fewer Persons) Community Living Arrangements

Author (date)	State	# Subjects Exp.	# Subjects Cont.	Age	Time (mths)	Level of MR Bord/ Mild	Level of MR Mod	Level of MR Sev	Level of MR Prof	Adaptive Behavior General/ Overall	Adaptive Behavior Specific Domains	Adaptive Behavior Problem Behavior
Bradley et al. (1986)	NH	80	80	AC	72	X	X	X	X	++	+ d	o
Close (1977)	OR	6	6	A	12			X	X		++ a	
Conroy et al. (1982)	PA	70	70	A	24	X	X	X	X	++		-[1]
D'Amico et al. (1978)	WV	6	7	AC	6,12[2]	X	X	X	X	++[3] ++[4]	++a,b,c,f o d,e	
Eastwood et al. (1988)	N.E. USA	49	49	A	24-48	X	X	X	X		++ c + a	
Rosen (1985)	AR	58	58	A	24	X	X	X	X	++	++a,d,e,f	
Schroeder et al. (1978)	NC	19	19	A	12			X		++		

[1] The movers stayed the same while the contrast group got worse.
[2] After measuring behavior at 6 months, 2 of the control subjects were randomly assigned to move to the community.
[3] Time 1 (4 exp., 9 cont.)
[4] Time 2 (6 exp., 7 cont.)

Outcomes
++ = statistically significant improvement relative to the contrast group
+ = improvement relative to the contrast group but not statistically significant
o = no change relative to the contrast group
- = decline relative to the contrast group but not statistically significant
-- = statistically significant decline relative to the contrast group

Adaptive Behavior Domains
a = self-care, domestic
b = communication/language
c = social skills
d = vocational
e = academic
f = community living
g = recreation/leisure

Age
A = adult
C = children
AC = adults and children

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Table A-2
Longitudinal Studies
Behavioral Outcomes Associated with Movement from State Institutions
to Small (15 or Fewer Persons) Community Living Arrangements

Author (date)	State	# Subjects	Age	Time (mths)	Level of MR				Adaptive Behavior		
					Bord/ Mild	Mod	Sev	Prof	General/ Overall	Specific Domains	Problem Behavior
Aanes et al. (1976)	MN	46	A	12	X	X	X	X		++ a,b,c o e,d,f	
Bell et al. (1984)	TX	66	AC	10	X	X	X	X		+ a,e	
Colorado Div. of DD (1982)	CO	115	AC	12	X	X	X	X	+		
Conroy et al. (1985)	PA	383[1]	AC	72[1]	X	X	X	X	++		+
Conroy et al. (1988)	CT	207	A	24	X	X	X	X	++	++ d	--
Feinstein et al. (1986)	LA	103	AC	9,18	X	X	X	X	++		++
Horner et al. (1988)	OR	23	AC	60	X	X	X	X		++ a,c,f	+
Kleinburg et al. (1983)	NY	20	A	4,8,12		X	X	X		++a[2],b,c o e,g - d	++[3] --[4]
O'Neil et al. (1985)	NY	27	A	3,9	X	X	X	X		++ a,b[5]	
Thompson et al. (1980)	MN	8	A	24			X	X	+[6]	+ a,b,f[6]	

[1] This study included 6 groups, all of which showed significant gains, the largest group measured over the longest time is reported here.
[2] Domestic skills increased significantly, but grooming skills showed no overall change.
[3] IQ above 20
[4] IQ below 20
[5] Significant increases were found in 4 of 16 subcategories in these skill areas.
[6] Mean differences were not tested for statistical significance.

Adaptive Behavior Domains
a = self-care, domestic
b = communication/language
c = social skills
d = vocational
e = academic
f = community living
g = recreation/leisure

Outcomes
++ = statistically significant improvement after move to the community
+ = improvement after move but not statistically significant
o = no change after move
- = decline after move but not statistically significant
-- = statistically significant decline after the move to the community

Age
A = adult
C = children
AC = adults and children

APPENDIX B: REFERENCES

References in Text

Bellman, W. (1971). [Remarks at 44720-44721 regarding ICF-MR provisions in Amendments to the Social Security Act]. 117 *Congressional Record* 44713, Senate, December 4, 1971, 44713-44786.

Boggs, E.M., Lakin, K.C., & Clauser, S.A. (1985). Medicaid coverage of residential services. In K.C. Lakin, B.K. Hill, & R.H. Bruininks (Eds.), *An analysis of Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF-MR) program*. Minneapolis: University of Minnesota, Center for Residential and Community Services.

Browne, C.M., & Walsh, C.A. (1989). Mid-level practitioners: Expanded roles. In I.L. Rubin & A.C. Crocker (Eds.), *Developmental disabilities: Delivery of medical care to children and adults*. Philadelphia: Lea & Febiger.

Davis, S. (1987). *National status report on waiting lists of people with mental retardation for community-based services*. Arlington, TX: Association for Retarded Citizens-United States.

Florida Developmental Services Program. (1988). *Comprehensive services plan for people with developmental disabilities: 1988-1992*. Tallahassee: Florida Department of Health and Rehabilitative Services.

General Accounting Office (1970). *Report to Congress: Questionable claims under Medicaid program for care of persons in state institutions for mentally retarded in California*. Washington, DC: Author.

Gettings, R.M., & Mitchell, D. (1980). *Trends in capital expenditures for mental retardation facilities: A state-by-state survey*. Washington, DC: National Association of State Mental Retardation Program Directors.

Hemp, R. (1989). Personal communication regarding statistics to be reported in D. Braddock, R. Hemp, G. Fujiura, L. Bachelder, & D. Mitchell (in press). Public expenditures for mental retardation and developmental disabilities in the United States: State profiles (3rd Ed.: FY 1977-1988). Baltimore: Paul H. Brookes.

Lakin, K.C. (1979). *Demographic studies of residential facilities for mentally retarded people: An historical review of methodologies and findings*. Minneapolis: University of Minnesota, Center for Residential and Community Services.

Lakin, K.C., Bruininks, R.H., & Sigford, B.B. (1981). Early perspectives on the community adjustment of mentally retarded people. In R.H. Bruininks, C.E. Meyers, B.B. Sigford, & K.C. Lakin (Eds.), *Deinstitutionalization and community adjustment of mentally retarded people*. Washington, DC: American Association on Mental Deficiency.

National Association for Retarded Citizens (1975). *Nursing homes in the system of residential services*. Arlington, TX. Author.

National Association of State Mental Retardation Directors (NASMRPD)(1989). Home and Community Based Waiver spending jumps by 50% in FY 1987-1988; Program participants rise to 29,400. *Community Services Reporter, 89*(16), whole issue. Presents data from Braddock, D., Hemp, R.,

Fujiura, G., Bachelder, L., & Mitchell, D. (in press). *Public expenditures for mental retardation and developmental disabilities in the United States*. Baltimore: Paul H. Brookes.

National Association of State Mental Retardation Program Directors (NASMRPD)(1989b). *Medicaid developments: Nursing home initiative* (April 10). Alexandria, VA: Author.

National Center for Health Statistics (1979). *The National Nursing Home Survey: 1977 Summary for the United States*. Hyattsville, MD: Author.

National Center for Health Statistics (1986). Prevalence, impact & demography of known diabetes in the United States. *Advance Data from Vital and Health Statistics* (No. 114, DHHS Pub. No. 86-1250). Hyattsville, MD: Public Health Service, February 12, 1986.

Scheerenberger, R.C. (1988). *Public residential services for the mentally retarded*. Madison, WI: National Association of Superintendents of Public Residential Facilities for the Mentally Retarded.

Sirrocco, A. (1988). *Nursing and related care homes as reported from the 1986 Inventory of Long-Term Care Places*. (Advance data #147). Hyattsville, MD: National Center for Health Statistics.

Taylor, S.J., Lakin, K.C., & Hill, B.K. (1989). Permanency planning for children and youth: Out of home placement decisions. *Exceptional Children, 55*(6), 541-549.

Uehara, E., Silverstein, B., Davis, R., & Geron, S. (in press). Assessment of the habilitation, medical and behavioral training needs of developmentally disabled adults in Skilled Nursing and Intermediate Care Facilities in Illinois. *Mental Retardation*.

References in Appendix A

Longitudinal Studies

Aanes, D., & Moen, M. (1976). Adaptive behavior changes of group home residents. *Mental Retardation, 14*, 36-40.

Bell, N., Schoenrock, C., & Bensberg, G. (1981). Change over time in the community: Findings of a longitudinal study. In R.H. Bruininks, C.E. Meyers, B.B. Sigford, & K.C. Lakin (Eds.), *Deinstitutionalization and community adjustment of mentally retarded people* (pp. 195-206). Washington, DC: American Association on Mental Deficiency.

Colorado Division of Developmental Disabilities (1982). *Colorado's regional center satellite group homes: An evaluation report*. Denver: Author.

Conroy, J.W., & Bradley, V.J. (1985). *The Pennhurst longitudinal study: A report of five years of research and analysis*. Philadelphia: Temple University Developmental Disabilities Center. Boston: Human Services Research Institute.

Conroy, J.W., Feinstein, C.S., & Lemanowicz, J.A. (1988). *Results of the longitudinal study of CARC v. Thorne class members*. (Report No. 7). Philadelphia: Temple University, Developmental Disabilities Center.

Feinstein, C.S., Lemanowicz, J.A., Spreat, S., & Conroy, J.W. (1986). *Report to the special master in the case of Gary W. v. the State of Louisiana*. Philadelphia: Temple University, Developmental Disabilities Center.

Horner, R.H., Stoner, S.K., & Ferguson, D.L. (1988). *An activity-based analysis of deinstitutionalization: The effects of community re-entry on the lives of residents leaving Oregon's Fairview Training Center.* Salem, OR: University of Oregon, Specialized Training Program of the Center on Human Development.

Kleinberg, J., & Galligan, B. (1983). Effects of deinstitutionalization on adaptive behavior of mentally retarded adults. *American Journal of Mental Deficiency, 88*, 21-27.

O'Neill, J., Brown, M., Gordon, W., & Schonhorn, R. (1985). The impact of deinstitutionalization on activities and skills of severely/profoundly mentally retarded multiply-handicapped adults. *Applied Research in Mental Retardation, 6*, 361-371.

Thompson, T., & Carey, A. (1980). Structured normalization: Intellectual and adaptive behavior changes in a residential setting. *Mental Retardation, 18*, 193-197.

Experimental/Contrast Group Studies

Bradley, V.J., Conroy, J.W., Covert, S.B., & Feinstein, C.S. (1986). *Community options: The New Hampshire choice.* Cambridge, MA: Human Services Research Institute.

Close, D.W. (1977). Community living for severely and profoundly retarded adults: A group home study. *Education and Training of the Mentally Retarded, 12*, 256-262.

Conroy, J., Efthimiou, J., & Lemanowicz, J. (1982). A matched comparison of the developmental growth of institutionalized and deinstitutionalized mentally retarded clients. *American Journal on Mental Deficiency, 86*, 581-587.

D'Amico, M.L., Hannah, M.A., Milhouse, J.A., & Froleich, A.K. (1978). *Evaluation of adaptive behavior. Institutional vs. community placements and treatment for the mentally retarded.* Stillwater, OK: Oklahoma State University, National Clearing House of Rehabilitation Materials.

Eastwood, E.A., & Fisher, G.A. (1988). Skill acquisition among matched samples of institutionalized and community-based persons with mental retardation. *American Journal on Mental Retardation, 93*, 75-83.

Rosen, D.B. (1985). *Differences in adaptive behavior of institutionalized and deinstitutionalized mentally retarded adults.* Ann Arbor, MI: University Microfilms International (DA8508127).

Schroeder, S.R., & Hanes, C. (1978). Assessment of progress of institutionalized and deinstitutionalized retarded adults: A matched-control comparison. *Mental Retardation, 16*, 147-148.

APPENDIX C: DISCUSSION GUIDE

INTERVIEW SCHEDULE

STATE CASE STUDIES ON MEDICAID LONG-TERM CARE SERVICES
FOR PERSONS WITH MR/DD

STATE _____

Respondent _____

Title _____

Agency _____

Address _____

_____

Telephone _____

Interviewer _____ Date _____

INTERVIEW SCHEDULE

STATE CASE STUDIES ON MEDICAID LONG-TERM CARE SERVICES
FOR PERSONS WITH MR/DD

I. **SUPPLY OF RESIDENTIAL SETTINGS**

A. **General Residential Services**

1. Based on information provided to us about your residential programs in general, we noted significant changes from 1977 to 1987. These included:

a. What have been the most significant factors influencing these changes? [Probe re: legislation, court decisions, formal (written) departmental goals, etc./note factors relevant to specific changes as appropriate]

b. [If not already covered in (a)] In what ways did these factors influence the trends in residential services?

c. Which of these factors would you say was the most influential in the changes noted? [Indicate with *] Why?

d. How could I obtain a description of the _____ above?

1. a. _____
_____

b. _____
_____

c. _____
_____

d. _____
_____

2. In a recent survey we asked for projections in your states overall residential services from June 1987 to 1990. Projected changes and factors of influence were reported as follows:

Type of facility	Projected Change	Factors

2. a(1) [State-operated facilities of 16 or more residents] What is the anticipated effect of _____ ? Why? [Repeat for each factor]

(2) [State-operated facilities of 15 or fewer residents] What is the anticipated effect of _____ ? Why? [Repeat for each factor]

(3) [Non-state facilities of 16 or more residents] What is the anticipated effect of _____ ? Why? [Repeat for each factor]

(4) [Non-state facilities of 15 or fewer residents] What is the anticipated effect of _____ ? Why? [Repeat for each factor]

b. Overall, which of these factors is anticipated to have the most significant effect on the residential services system? Why?

c. How can I obtain a description of _____ _____ [interrelationship between projections and significant trends]?

3. Does your state presently have waiting lists for residential care or other indications of people waiting for residential services?

a. How many people are presently awaiting residential services? [Note any references to numbers in need of specific types of residential services]

b. Are the needed services primarily for a specific type of residential care? Why?

2. a(1) _____

(2) _____

(3) _____

(4) _____

b. _____

c. _____

3. YES / NO

a. _____

b. YES / NO _____

3. c. Are there any groups (e.g., age groups, people with certain types or levels of disability) that are particularly evident in these waiting lists? Which ones?

d. Are the needed services primarily in specific geographic areas of the state? Which ones?

e. How has the size of waiting lists changed over the last 4 or 5 years?

f. Are there documents that I could obtain on waiting lists, unmet needs or future demands for service?

4. Are there any programs provided as alternatives to residential care or which may serve to reduce the demand for residential care? For example, is there:

a. A family cash subsidy program

b. Respite care

c. Other family support (e.g., homemaker, home health aide services)

d. Nonresidential case management

e. Other _____

f. Other _____

g. Other _____

h. Which of these programs has the biggest effect on reducing demand for residential care (circle)? Why?

i. Are any of the programs not presently offered under development? Which?

j. When is the anticipated implementation? What influence on the demand for residential care is expected?

3. c. YES / NO _____

d. YES / NO _____

e. _____

f. _____

	Y/N	Number People/ Facilities Served	How much/what effect program has on the need for long-term care
a			
b			
c			
d			
e			
f			
g			

h. _____

i. _____

j. _____

B. Title XIX Residential Services

1. From survey information provided on ICF-MR utilization, notable changes took place between 1977 and 1987 in [total residents, non-state facilities, small facilities]:

a. What specific factors were significant influences on these changes? [Indicate which change was affected as appropriate]

1. a. _____

_____

_____

_____

2. Survey projections in ICF-MR residential services from June 1987 to 1990 and reported factors of influence and considerations were:

Type of ICF-MR	Projected Change	Factors

a(1) [State-operated ICF-MR facilities of 16 or more residents] What is the anticipated effect of _____ ? Why? [Repeat as needed for each factor mentioned]

a(1) _____

_____

_____

(2) [State-operated ICF-MR facilities of 15 or fewer residents] What is the anticipated effect of _____ ? Why?

(2) _____

_____

_____

(3) [Non-state ICF-MR facilities of 16 or more residents] What is the anticipated effect of _____ ? Why?

(3) _____

_____

2. a(4) [Non-state ICF-MR facilities of 16 or more residents] What is the anticipated effect of _____ ? Why?

(4) _____

b. Which of these factors/considerations is expected to have the most influence on ICF-MR utilization? Why?

b. _____

c. Are there other factors that are likely to have a significant influence on residential services in the near future? In what way?

c. YES / NO _____

d. Are there any potential barriers to these changes or factors that could significantly change the anticipated 1990 ICF-MR projections? In what way(s)?

d. YES / NO _____

3. [IF USING WAIVER] The state's Home and Community-Based Services Waiver (HCBS) is in its _____ year. As of June 30, 1987 it was indicated that about _____ individuals with mental retardation/developmental disabilities were receiving services under the waiver.

3. a. Actual _____ Approved _____

a. How many individuals are currently receiving waiver services? How many are approved for services?

b. Are services under the HCBS waiver focused primarily on individuals with any particular characteristics? What are they? What have been the results?

b. YES / NO _____

c. What percentage of Medicaid waiver recipients are living in residential settings with supervision from persons other than natural or adoptive family members?

c. _____

d. Has the use of the HCBS Waiver affected the overall utilization of ICF-MR services? How?

d. YES / NO _____

3.	e.	Have other residential services been affected? How?	3. e. YES / NO _____
	f.	What are the major strengths of the HCBS Waiver in meeting long-term care needs for persons with MR/DD in the state?	f. _____
	g.	What are the waiver's limitations (if any) in responding to state needs?	g. _____
	h.	Are there notable differences in the characteristics of persons receiving waiver services and those residing in ICF-MR facilities? What are they? (Probe re: age, nature or level of disability, family living status, etc.)	h. YES / NO _____
	i.	Does the state plan to renew its HCBS waiver? If yes, when? If no, why not?	i. YES / NO _____
	j.	How could I obtain a summary of the state's use of the waiver for persons with MR/DD?	j. _____
4.		(IF NOT CURRENTLY USING WAIVER) Does the state plan to apply for a Home and Community-Based Services Waiver in the near future?	4. YES / NO
5.		(FOR STATES PLANNING TO APPLY)	
	a.	When do you expect use of the waiver to begin?	5. a. _____
	b.	How many individuals with MR/DD do you expect will receive services after full implementation?	b. _____
	c.	What percentage will live in residential settings with supervision from persons other than natural or adoptive family members?	c. _____
	d.	Do you expect the use of the HCBS Waiver to affect the overall utilization of ICF-MR services? How?	d. YES / NO _____
	e.	To affect other residential services? How?	e. YES / NO _____

5. f. Do you expect there will be notable differences in the characteristics of waiver service recipients and residents of ICF-MR facilities? What are they? (Probe for differences in age, nature and level of disability, family status, etc.)

g. What are the major strengths of the waiver in meeting the long-term care needs for persons with MR/DD in the state?

h. Why has the state not obtained a waiver previously? (Probe: What are the waiver's limitations in responding to state needs?)

6. (FOR STATES NOT USING AND NOT PLANNING TO USE THE WAIVER)

a. How does the Home and Community-Based Services Waiver as presently available fail to meet the state's needs? What is the primary reason the state is not participating in the waiver?

b. What changes would make the waiver more attractive in relation to state needs?

7. (FOR STATES USING/PLANNING TO USE OTHER MEDICAID OPTIONS) The recent survey responses included information on the state's use of other relevant Medicaid options (list options from survey response):

a. Which of those are currently in effect and which are planned? (For planned options) What is the expected date of implementation?

5. f. TBI / MD _____

g. _____

h. _____

6. a. _____

b. _____

7. a. Current Planned Year of Implementation

7. b. What is/are the major factor(s) in the decision to use [for each option]:

(1) _____

(2) _____

(3) _____

(4) _____

c. Are these options affecting/expected to affect the ICF-MR program? In what ways?

d. Are they affecting/expected to affect other residential services? In what ways?

8. [IF NOT USING/PLANNING TO USE OTHER OPTIONS] What are the state's major considerations in the decision not to use other Medicaid options such as case management, personal care, habilitation services, etc.?

II. APPROPRIATENESS OF PLACEMENTS

1. Have the characteristics of residents in ICF-MR facilities in general or in any specific type of ICF-MR facility changed notably in recent years? In what ways? [Probe re: proportion of children, nature and severity of disability, other]

7. b. (1) _____

(2) _____

(3) _____

(4) _____

c. YES / NO _____

d. YES / NO _____

8. _____

1. YES / NO _____

2. The response to the recent survey indicated that there is currently _____

_____

policy governing the (number or characteristics) of persons who can be admitted to large state facilities.

a. Are there other policies/practices limiting such placements in relation to individual characteristics? What are they?

b. Are there similar policies affecting placements in other types of residential services? (Probe re: family/foster care, large private facilities, other)

c. To what extent are these written, formal policies or customary practice?

d. To what extent do these policies or practices vary <u>within</u> the state?

e. Have these policies/practices affected trends in the use of the ICF-MR program? In what ways?

3. What are the major criteria used to determine that an ICF-MR level of care is needed by an individual? (Probe re: criteria more specific than federal standards)

a. Who is responsible for defining these criteria?

b. Are there any standards defining the nature and/or level of disability considered to justify placement in an ICF-MR level of care beyond those in the federal regulations? Are these written or informal? What are they?

c. Is there currently concern that some individuals receiving ICF-MR services might benefit from less restrictive models of residential care? (Probe for extent of issue, numbers affected, characteristics of affected individuals) How is the state responding to these concerns?

2. a. YES / NO _____

b. YES / NO _____

c. _____

d. _____

e. YES / NO _____

3. _____

a. _____

b. YES / NO _____

c. YES / NO _____

3. d. What are the respective roles and responsibilities of state and local agencies for:

(1) Placement in an ICF-MR certified facility

(2) Placement in a non-certified residential facility

(3) Case management in an ICF-MR certified facility

(4) Case management in a non-certified residential facility

4. Will residential placements of individuals with MR/DD be affected by implementation of the Omnibus Reconciliation Act (P.L. 100-203) requirements requiring placement of such individuals in nursing homes only when nursing services are needed and that active treatment be available as appropriate? In what ways?

a. What was the state's policy on nursing home placements prior to P.L. 100-203?

b. Has the state conducted a review of nursing home placements? What were the major findings?

c. Is there a written report? How could I obtain a copy?

d. What effects of P.L. 100-203 (review, placement criteria, etc.) are anticipated on the number of individuals with MR/DD in nursing homes? Are any particular population groups expected to be particularly affected? Which ones? [Probe re: age, nature and level of disability, other]

e. What effects are anticipated on state institutions? On other residential services?

III. EFFICIENCY IN STATE EXPENDITURES

1. What are the most pressing issues in financing the state's residential care system? [Probe for growth in overall costs/limits on appropriated funds; increased numbers of clients; increase in unit costs; other]

3.d. _____

State Local

(1) _____

(2) _____

(3) _____

(4) _____

4. YES / NO _____

_____

_____

a. _____

_____

b. _____

_____

c. YES / NO _____

_____

d. YES / NO _____

_____

e. _____

_____

1. _____

_____

1. a. Have costs for some types of residential facilities grown disproportionately? Which type(s)? [Probe re: increased cost per resident in institutions]

   b. Is the competition for resources among service programs an issue? How is this affecting the residential service system?

2. What are the primary economic considerations when the state makes decisions about possible expansion of the ICF-MR program?

   a. For what types of facilities is ICF-MR particularly cost-effective for the state?

   b. For what types of residents? [Probe re: level and nature of disability, age, other]

   c. For what type of operator? [state, other public, private non-profit, private for-profit]

   d. Any other special considerations?

3. Do different rates of reimbursement tend to be paid to public and private ICF-MR facilities for clients of similar characteristics? How would private facility reimbursement be estimated as a percentage of public facility reimbursement?

4. Are differences in reimbursement rates for public and private facility services (either ICF-MR or non-ICF-MR) an issue in the state? How is it being addressed?

   a. Are differences in public and private facility personnel costs an issue? How is that issue being addressed?

   b. What effect do these cost/reimbursement issues have on plans for the residential care system?

1. a. YES / NO _____

b. YES / NO _____

2. _____

a. _____

b. _____

c. _____

d. _____

3. YES / NO _____

_____ %

4. YES / NO _____

a. YES / NO _____

b. _____

5. Does the state use or is it considering alternative methods of facility reimbursement? What are they? [If considering] When will they be implemented?

   a. [If relevant] What is the primary purpose of these methods? [Probe re: cost control, redistribution of available funding]

   b. What effect does/will this have on the residential care system?

6. How are funding responsibilities divided among levels of government for services in state ICF-MR institutions and other types of facilities? [Indicate percentage of funding responsibility for each type of facility; include federal SSI as federal and state SSI supplement as state; probe for any differences in private vs. local public among non-state facilities]

   a. Are there any notable incentives or disincentives for certain kinds of placements that might be associated with the division of responsibility for funding? What are they?

   b. Are individual and family members ever required to share in residential service costs (not including SSI benefits)? To what extent and under what circumstances?

IV. **QUALITY ASSURANCE**

1. Regarding the state's quality assurance program, are there any differences in the frequency, nature, or responsible agency for monitoring program quality in public vs. private ICF-MR facilities? What are they?

   a. Between small and large ICF-MR facilities? What are they?

   b. Between monitoring of ICF-MR certified and non-certified residential facilities? What are they?

5. YES / NO _____

a. _____

b. _____

	Federal	State	Local
State Operated ICF-MR			
Non-State ICF-MR			
Other Non-State Non-Certified			

a. YES / NO _____

b. YES / NO _____

1. YES / NO _____

a. YES / NO _____

b. YES / NO _____

2. Have any ICF-MR facilities been threatened with decertification as a result of HCFA "Look-Behind" review? How many? Public or private?

   a. Did any facility actually lose certification? Which ones?

   b. What was the state's perspective on the HCFA reviews?

   c. Are there any lasting repercussions of the federal "Look-Behind" activity? (Probe re: any significant shifts in resources in order to meet requirements)

3. What effects are anticipated from the implementation of the new ICF-MR regulations?

4. What is the major quality assurance issue affecting the state's residential care system? Why?

V. PROGRAM CONTEXT

1. How would you describe the overall set of goals, principles or objectives that guides the residential care system?

   a. To what extent do these influence the development of the residential care system? In what ways?

   b. How could I obtain a description of these goals?

2. YES / NO _____

a. YES / NO _____

b. _____

c. YES / NO _____

3. _____

4. _____

1. _____

a. _____

b. _____

2. [If not already answered] To what extent is decision-making centralized in relation to design of the system for residential and related services? [Probe re: variation within the state, effects of state policy on local services]

3. [If not already answered] What is the basic division of responsibility among state agencies for the ICF-MR program?

   a. For other residential services?

   b. For related services?

   c. What are the most significant inter-agency issues affecting the residential service system? Why?

4. Follow-up: _____

_____

_____

_____

_____

_____

_____

2. _____

3. _____

a. _____

b. _____

c. _____